

Recruitment, use, and satisfaction with a web platform supporting families of children with suspected or diagnosed developmental coordination disorder: A randomized feasibility trial.

Journal:	Developmental Neurorehabilitation
Manuscript ID	Draft
Manuscript Type:	Original Research
Keywords:	Developmental disabilities, Motor delay, Web-based services, Internet, Service delivery

SCHOLARONE™ Manuscripts

1	
2	Recruitment, use, and satisfaction with a web platform supporting
3	families of children with suspected or diagnosed developmental
4	coordination disorder: A randomized feasibility trial
5	
6	ABSTRACT. Current: 150 words.
7	Objectives. To determine the feasibility of recruiting families of children with suspected
8	or diagnosed developmental coordination disorder (sdDCD) and explore their satisfaction
9	with a webplatform aimed at supporting them.
10	Design . A feasibility randomized trial was needed before conducting a full trial.
11	Participants were parents of children aged 5-12 years old with sdDCD. The intervention
12	group had access to online resources, group and private forums, and videoconferencing
13	with a therapist. Main outcomes were the recruitement and retention rates. Satisfaction
14	was documented through a post-intervention survey and interview.
15	Results. Recruitment rate was 7 participants/month (n=28 participants) and retention rate
16	was 68%. Satisfaction was moderate. Participants formulated various recommendations
17	for improving the intervention, including targeting families earlier in the diagnosis
18	process, and pre-scheduling meetings with therapists.
19	Conclusions. Results demonstrated the feasibility of future trials evaluating
20	webplatforms aimed at supporting children with sdDCD. Improvement areas were
21	identified to ensure greater relevance of the intervention.

1 Keywords: Developmental disabilities, Motor delay, Web-based services	Internet
-------------------------------------------------------------------------	----------

Service delivery

- List of abbreviations: DCD: Developmental Coordination Disorder; sdDCD: suspected or
- diagnosed Developmental Coordination Disorder; RCT: randomized controlled trial Word count: 3011



INTRODUCTION

3 Developmental coordination disorder (DCD) affects 5-6% of school-aged children and

impacts the learning and performance of motor tasks. 1 Children with DCD are under-

served, face long wait times, and are often ineligible for specializedrehabilitation

services.² Early intervention could prevent DCD-related secondary consequences, such

as social isolation, anxiety and reduced cardiorespiratory fitness.²⁻⁸ Telerehabilitation,

known to increase access to care and foster chronic care management⁸⁻¹⁰, offers

interesting opportunities to implement early DCD interventions according to best

practices, which state that families should be empowered to manage their child's

condition through population-based response-to-intervention models, where universal

design interventions (e.g., information, capacity-building) should be offered first, before

moving to group- or individual-based interventions.^{2,11}

Previous research has shown that a DCD online module can increase parental knowledge

but was limited in supporting DCD management.¹² Only one low-quality publication

reported parental satisfaction with a web platform providing general information about

DCD, but no control group was used and authors did not thoroughly describe the use of

the platform nor explore its impact on managing DCD.¹³ The feasibility of delivering

early online DCD interventions is currently unknown but important to document prior to

conducting a full trial evaluating their effectiveness.

The primary goal of this study was to determine the feasibility of recruiting and retaining families with children with suspected or diagnosed DCD (sdDCD) in a trial evaluating a webplatform aiming to support families. Secondary objectives were to: (1) determine whether the intervention was feasible (i.e. if families would use the webplatform and the therapist would be able to deliver the intervention); and (2) explore participant satisfaction.

METHODS

Design

A parallel, 2-group, randomized (1:1), double-blinded feasibility trial (NCT03141333) was conducted from September 2016 to June 2017. A sequential mixed method design was used. The study was approved by our Institutional Ethics Board. Two changes were made after the trial started to increase feasibility of recruitment: only children with intellectual or physical disability and autism spectrum disorder were excluded, and participants who had a recent (<1 year) professional evaluation of the Movement Assessment Battery for Children-Second Edition (MABC-2) were allowed to submit their report instead of coming to the research centre for evaluation.

Participants

Inclusion criteria were to be the parent or legal guardian of a child aged 5-12 years old with sdDCD (diagnosed DCD or referred by a family doctor for specialized assessment) who had not yet received DCD-specific rehabilitation interventions. Initial screening was done over the phone. In-person eligibility assement at the research centre ensured children met DCD international guidelines with regards to MABC-2¹⁵ and DCD-Questionnaire (DCD-Q)¹⁶ scores. Informed consent was sought following the eligibility assessment.

Study procedures, Randomization & Blinding

Figure 1 illustrates the recruitment procedure and the number of potential participants screened and assessed. Participants were recruited from September 2017 to January 2018. In mid-January, all participants were asked to complete the baseline questionnaire online, and respondents were randomized to either the control or intervention group (ratio 1:1) using a computer-generated list, with random blocks of 2 and 4. The list was managed by an individual external to the project. Two weeks later, the platform manager, who was blinded to participant scores, sent individualized codes granting access to a webpage listing DCD resources (control group), or the full platform (intervention group). Participants were made aware of their group allocation once they logged into the platform. After the 3-month intervention period, participants were asked to complete the post-intervention questionnaire online. To evaluate the impact of adding participants on the webplatform, all participants were granted full access to the platform for an additional

1 month. Investigators were blinded to all outcomes when quantitative data were collected

and analyzed. One month later, qualitative data were collected via phone interviews (see

appendix 1 in supplemental online material).

Intervention

The intervention consisted of a web-based platform offering online rehabilitation resources and services that participants could access anytime on a voluntary basis. The information available on the platform was developed according to DCD best practices, including response-to-intervention and task-oriented, participation-focused and capacity-buiding approaches. ^{2,11,17} The platform included four components: (1) DCD online resources including links to relevant and high-quality webpages such as an evidence-based module; ¹² (2) a forum where participants were encouraged to post questions and interact with other participants and an occupational therapist, who acted as an expert, knowledge broker and forum moderator; ¹⁸ (3) a private chat function for communicating directly with the therapist; and (4) a videoconference system. Participants were encouraged to use the platform sequentially, trying to find answers to their concerns via the static resource page or forum first, before contacting the therapist directly. The therapist was instructed to only invite families to use videoconferencing if contact via the private chat function was deemed insufficient.

The webplatform manager was available to provide technical support throughout the study. The therapist moderating the forum was initially instructed to wait for the parents' questions, but was asked after a month to publish new discussion topics (e.g., leisure activities) on a weekly basis to foster greater use of the forum. The therapist reached out to each participant via the private chat function, and the webplatform manager sent an email half-way through the intervention to summarize discussion threads and to encourage participants to visit the webplatform.

Outcomes

Recruitment and retention

The number of potential participants reached, screened, assessed for eligibility, deemed eligible, randomized, and retained until the post-intervention survey were computed for each recruitment method. Recruitment rate was defined as the average number of participants recruited per month. Retention rate was defined as the percentage of recruited participants who completed the post-intervention questionnaire.

Use of the Web Platform

The participation rate documented the number of participants who accessed the web platform at least once. Platform utilization data, such as the number of visits to the platform, time spent, pages visited, and content generated (new topics or posts on the

Satisfaction

The post-intervention questionnaire evaluated general satisfaction, satisfaction-related concepts (e.g., How useful was the platform), and general use of the Internet and social media. This last question was included to explore if a greater score would be related to a greater use of the platform.

Qualitative data.

To gain a deeper understanding of their perspectives about the platform, 30-minute semi-structured phone interviews were conducted with 12 participants selected to ensure maximum variation in the sample (e.g., use of the platform, group allocation, survey responses, diagnostic status). Questions pertained to factors influencing platform use and navigation, perceptions about telerehabilitation, and recommendations for future studies.

22 Analysis

- 1 Recruitment and retention were described using count and percentages. For participants,
- 2 non-parametric descriptive statistics were used to describe sociodemographic, MABC-2
- 3 and DCD-Q results.

- 5 Platform utilization and satisfaction data were described using medians and quartiles.
- 6 Mann-Whitney tests were performed to explore whether these outcomes were different
- 7 between groups.

- 9 Interviews were transcribed and analyzed using NVivo. A content analysis using a mixed
- deductive-inductive approach¹⁹ based on the interview guide was used. A research
- assistant inductively coded all transcripts, which were then reviewed by the principal
- investigator before meeting with the research assistant to discuss the interpretation of
- results and validate themes. An individual and group summary of the interviews were
- sent to participants for validation.

RESULTS

Subject recruitment, retention, and sociodemographics

- 21 Figure 1 illustrates the flow diagram. Out of 118 participants screened over the phone, 28
- were eligible, consented to participate, completed the baseline questionnaire and were
- randomized. Of those, 21 families were awaiting a clinical assessment and 7 families

1	contacted us (4 referred by family doctors, 2 saw publicity on social media, and 1 from
2	word-of-mouth) (see appendix 2 in supplementary online material for more details about
3	recruitment per method of recruitement). The recruitment rate was 7 participants/month
4	and the retention rate was 68%.
5	
6	Sociodemographic characteristics are presented in Table 1. No differences were found
7	between groups pre-intervention, or between those who completed the post-intervention
8	survey and those who did not.
9	
10	(Insert Figure 1 and Table 1 about here)
11	
12	
13	Use of the platform
14	
15	The participation rate was 72%, since 6 participants never accessed the webplatform. The
16	median number of visits was of 1 and 2, for the intervention and control groups,
17	respectively (Table 2). There were no significant differences between groups with regards
18	to platform utilization. In the intervention group, 2 participants created new discussion
19	topics on the forum, 5 participants contributed responses to those topics, 2 participants
20	contacted the therapist privately, and no webconference was organized.
21	

(Insert Table 2 about here)

Table 2 also presents utilization data for the therapist and the webplatform manager. Therapist outcomes were consistent with the data obtained via the therapist's weekly activity log (median of 30 minutes/week, ranging from 5 to 120 minutes). Almost all the therapist' time was dedicated to forum activities (median: 22.5 minutes), with medians at 0 for the use of the private chat, videoconferencing or other project-related activity (e.g., research meetings). The therapist reported only one meaningful interaction over the private forum, pertaining to a child's anger management. Another question sent privately was redirected by the therapist towards the forum, as it was a relevant topic for all participants. The therapist did not report any technical issues or concerns with managing participant interactions.

Satisfaction

Table 3 presents the post-intervention questionnaire results. Ease of navigation was high but satisfaction and perceived usefulness ranged between low to moderate. Participants reported using the Internet only moderately to find information about DCD, and this score did not influence other scores or the use of the platform. No statistical differences were found between groups on any of the five scores.

(Insert Table 3 about here)

Qualitative results

Figure 2 illustrates the five inter-related themes, along with their subthemes, that emerged from the interviews. Themes were common to all participants independently of their allocation group. Perceived usefulness relates to the usefulness of the platform as a whole. The most positive aspect was perceived to be that relevant DCD information was aggregated. However, many participants already knew this information and reported having needs that could not be met by the platform (e.g., neuropsychological assessement). They suggested the platform be used for families having early developemental concerns or having recently received a DCD diagnosis, and those who could not afford private in-person services. Not receiving any public or private services appeared to positively influence the perceived usefulness of the platform, as well as some family characteristics (e.g., low DCD knowledge, perceiving their child as having mild DCD, being social and comfortable with technology). *Perceived usability* pertains to ease of navigation on the platform and was influenced by the participants' ease with technology. Technical difficulties was one of the other factors influencing platform utilization. Most parents reported having consulted the platform for general information or by curiosity, but expected to have a stronger motivation to consult the platform in the event of facing particular issues with their child.

(Insert Figure 2 about here)

The *impact of the platform* refers to the perceived impact of using the platform on the families. Some reported little impact because they already knew most of the information while others reported a general increase in DCD knowledge and a concrete impact on their children's daily lives (viaspecific sensory exercises or recommendations for leisure). Participants had many *recommendations for increasing the utilization and impact* of the platform. Participants suggested to include scheduled activities, such as having predetermined meetings with the therapist or having online "walk-in clinic" time slots and punctual activities (e.g., webinars). Improving functionalities and clarifying the expected utilization refers to ensuring all participants are aware and can easily access all aspects of the intervention. Subscribing to threads and receiving a summary of activities by email were perceived to be interesting options, but linking the platform to social media accounts was also suggested. Including more participants (not only more parents but also children, other clinicians, and stakeholders, such doctors and teachers) and

ensuring the intervention lasts longer were also suggested.

DISCUSSION

This feasibility study was the first randomized-controlled trial (RCT) exploring an online intervention supporting children with sdDCD and their families. Results demonstrated the feasibility of conducting a future RCT to evaluate the impact of a webplatform and identified important recommendations to increase recruitment and retention, platform utilization, and satisfaction with the intervention.

Recruiting participants with sdDCD was feasible with a recruitement rate of 7 participants/month. Comparing the recruitment rate with other studies is difficult, given the paucity of DCD RCTs and the lack of information with regards to recruitment, but our rate is lower compared to another online DCD study that required no eligibility assessment¹². Our final sample size is comparable to other RCT clinical studies but the retention rate was lower. 20,21 Loss to follow-up in web-based interventions is generally reported to be higher and our retention rate is comparable to other web-based studies in other fields.²² To increase retention for future DCD web-based interventions, several recommendations might be formulated. First, the delay between eligibility assessment and the launch of the platform should be minimal. In the present study, four months had elapsed and some participants likely lost interest in the study and developed new priorities. Secondly, qualitative results highlighted the importance of personal interactions. Ensuring personal contacts throughout the study process, in person, via a webplatform or the phone, could help retention. Likewise, planning scheduled events and meetings with the therapist could not only promote the utilization and relevance of the platform, but also foster personal relationships with and within participants to help retention.

The analysis of the number of participants contacted, assessed, and enrolled in the study provides helpful insights for future web-based DCD trials. Contacting families waiting for assessment was time consuming but effective in recruiting participants. However, the longer families had been waiting, the less likely they were to be eligible to – or interested

in – the intervention. Offering this type of intervention just-in-time seems particularly important. Based on our qualitative findings, the type of service proposed might be particularly useful when parents have developmental concerns, before children are referred for specialized assessment. Increasing recruitment efforts through collaboration with family doctors and community-based professionals might ease recruitment for future trials, and will likely contribute raising awareness of DCD among those groups. Finally, social media, which had been particularly helpful for other DCD online studies, did not lead to much recruitment. This is somewhat surprising but might be explained by the fact that social media users might have not considered the proposed intervention as adding value to what was already available on traditional social media (e.g., Facebook parent groups). This finding warrants more study and future trials should optimize recruitment materials to clearly explain the online intervention and distinguish it from traditional social media.

Utilization data demonstrated the feasibility of using the intervention, both by parents and the therapists. A web-based DCD study targeting rehabilitation professionals reported similar usage trends, with some participants not using the platform at all and others using it frequently. Caution needs to be taken while interpreting utilization data, which might seem to be low, particularly for the private chat and videoconferencing functions. Other studies of online interventions have reported the importance of timely access to information or services as opposed to repeatedly accessing the information.

Participants reported high scores for ease of use but interviews revealed that some were not aware that they could privately contact the therapist. The fact forums are intuitive might mislead parents and future studies should ensure participants are well-aware of all aspects of the intervention, via in-person training instead of a static user guide. Our findings also suggest parents need to be better supported, with the therapist assuming a more proactive role and reaching out to families as opposed to waiting for questions. Although our findings indicate that the proposed intervention requires little therapist time, this result needs to be interpreted with caution, since many of the pre-intervention meetings with the therapist were not captured by the data collection, and greater participant activity on the platform might impact therapist time. Exploring how interdisciplinary teams could provide the intervention is an interesting avenue for further study.

Satisfaction was generally moderate, but qualitative findings suggest parents appreciated knowing the therapist was available, if and when needed. Our participants made various recommendations that could help increase the relevance of the intervention, as well as improve recruitment and retention. Caution should be taken while designing web-based interventions integrating DCD best practice, as the recommended principle of response-to-intervention might apply differently to a virtual setting. In our design, video-conferencing was perceived to be a Tier-3 intervention but given the importance of personal interactions, regularly scheduled activities should be planned proactively while delivering services online. Further research, partnering with web designers and applying web ergonomics models, should explore how web-based interventions can be integrated

early on in the continuum of care, and be combined with face-to-face interdisciplinary assessements and interventions, so as to better align current services with DCD best practices.

Study Limitations

Limitations of this study include biases related to the automatic data tracking system (e.g., under- or over-estimating active platform time on the platform). The postintervention questionnaire was self-reported and not validated. These biases were diminished by the addition of interviews that provided in-depth information about use and satisfaction. Policy.

CONCLUSION

There are numerous challenges related to the undertaking of an RCT exploring the impact of a web-based platform for children with DCD, mostly related to recruitment, as well as the design and timing of the intervention. This type of intervention might be an interesting complement to current practices. Implementing the recommendations formulated by the parents would likely improve the feasibility of such a trial. Ensuring the intervention includes a greater number of participants for a longer period of time also appears to be important, and might call for a multi-site approach.

REFERENCES

- American Psychiatric Association. *Desk Reference to the Diagnostic Criteria from DSM-5*.; 2014.
- Missiuna C, Polatajko HJ, Pollock N. Strategic management of children with developmental coordination disorder. In: Cairney J, Cairney J (Ed), eds.
 Developmental Coordination Disorder and Its Consequences. Toronto, ON,
- 7 Canada: University of Toronto Press; 2015:215-252.
- 8 3. Rivilis I, Hay J, Cairney J, Klentrou P, Liu J, Faught BE. Physical activity and fitness in children with developmental coordination disorder: a systematic review.

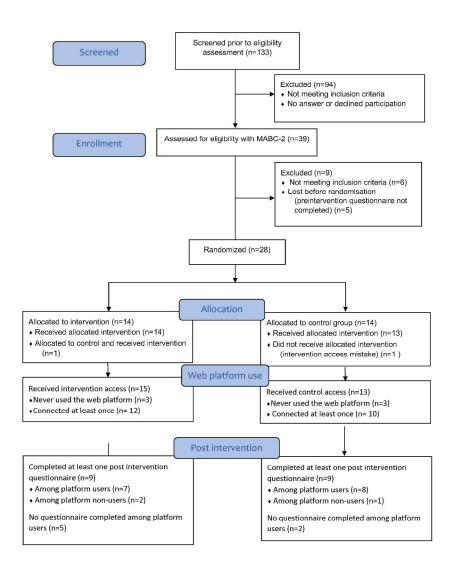
 10 Res Dev Disabil. 2011;32(3):894-910. doi:10.1016/j.ridd.2011.01.017
- Cairney J, Hay JA, Faught BE, Wade TJ, Corna L, Flouris A. Developmental coordination disorder, generalized self-efficacy toward physical activity, and participation in organized and free play activities. *J Pediatr*. 2005;147(4):515-520. doi:10.1016/j.jpeds.2005.05.013
- Missiuna C, Cairney J, Pollock N, et al. Psychological distress in children with developmental coordination disorder and attention-deficit hyperactivity disorder.
 Res Dev Disabil. 2014;35(5):1198-1207. doi:10.1016/j.ridd.2014.01.007
- Cairney J, Hay JA, Faught BE, Hawes R. Developmental coordination disorder and overweight and obesity in children aged 9–14 y. *Int J Obes*. 2005;29(4):369-372.
 doi:10.1038/sj.ijo.0802893
- Cairney J, Hay J, Veldhuizen S, Missiuna C, Mahlberg N, Faught BE. Trajectories of relative weight and waist circumference among children with and without developmental coordination disorder. *Can Med Assoc J J Assoc Medicale Can*.
 2010;182(11):1167-1172. doi:10.1503/cmaj.091454
- Edirippulige S, Reyno J, Armfield NR, Bambling M, Lloyd O, McNevin E.
 Availability, spatial accessibility, utilisation and the role of telehealth for multi-disciplinary paediatric cerebral palsy services in Queensland. *J Telemed Telecare*.
 2016;22(7):391-396. doi:10.1177/1357633X15610720
- Iacono T, Stagg K, Pearce N, Hulme Chambers A. A scoping review of Australian allied health research in ehealth. *BMC Health Serv Res.* 2016;16(1):543-543.
- Camden C, Fallon F, Pratte G, Couture M, Berbari J, Tousignant M. (submitted to
 Disability and Rehabilitation) Are teleinterventions effective for providing
 paediatric rehabilitation? Results from a systematic review.
- Camden C, Wilson B, Kirby A, Sugden D, Missiuna C. Best practice principles for
 management of children with developmental coordination disorder (DCD): results
 of a scoping review. *Child Care Health Dev.* 2015;41(1):147-159.
 doi:10.1111/cch.12128

- 1 12. Camden C, Rivard L, Pollock N, Missiuna C. Knowledge to practice in
- 2 developmental coordination disorder: impact of an evidence-based online module
- on physical therapists' self-reported knowledge, skills, and practice. *Phys Occup*
- 4 Ther Pediatr. 2015;35(2):195-210. doi:10.3109/01942638.2015.1012318
- 5 13. Miyahara M, Butson R, Cutfield R, Clarkson JE. A pilot study of family-focused
- 6 tele-intervention for children with developmental coordination disorder:
- 7 development and lessons learned. Telemed J E-Health Off J Am Telemed Assoc.
- 8 2009;15(7):707-712. doi:10.1089/tmj.2009.0022
- 9 14. Creswell, John W., Plano Clark, Vicki L., Gutmann, Michelle L., Hanson, William
- 10 E. Handbook of Mixed Methods in Social & Behavioral Research. Sage
- Publications, Inc.; 2003.
- 12 15. Henderson SE, Sudgen, David A., Barnett, Anna. Movement Assessment Battery
- for Children: 2nd Edition (MABC-2). In: Encyclopedia of Autism Spectrum
- 14 Disorders. Springer, New York, NY; 2013:1925-1939. doi:10.1007/978-1-4419-
- 15 1698-3 1922
- 16. Wilson BN, Crawford SG, Green D, Roberts G, Aylott A, Kaplan BJ. Psychometric
- 17 Properties of the Revised Developmental Coordination Disorder Questionnaire.
- 18 Phys Occup Ther Pediatr. 2009;29(2):182-202. doi:10.1080/01942630902784761
- 19 17. Smits-Engelsman BCM, Blank R, Van Der Kaay A-C, et al. Efficacy of
- interventions to improve motor performance in children with developmental
- 21 coordination disorder: a combined systematic review and meta-analysis. *Dev Med*
- *Child Neurol.* 2013;55(3):229-237. doi:10.1111/dmcn.12008
- 23 18. Hurtubise K, Rivard L, Héguy L, Berbari J, Camden C. Virtual knowledge
- brokering: describing the roles and strategies used by knowledge brokers in a
- 25 pediatric physiotherapy virtual community of practice. J Contin Educ Health Prof.
- 26 2016;36(3):186. doi:10.1097/CEH.000000000000101
- 27 19. Miles MB, Huberman AM. Qualitative data analysis: an Expanded Sourcebook.
- Beverly Hill; London: Sage Publications, c1994.; 1994.
- 29 20. Straker LM, Campbell AC, Jensen LM, et al. Rationale, design and methods for a
- randomised and controlled trial of the impact of virtual reality games on motor
- 31 competence, physical activity, and mental health in children with developmental
- 32 coordination disorder. *BMC Public Health*. 2011;11:654. doi:10.1186/1471-2458-
- 33 11-654
- 34 21. Fong SSM, Tsang WWN, Ng GYF. Taekwondo training improves sensory
- organization and balance control in children with developmental coordination
- disorder: a randomized controlled trial. Res Dev Disabil. 2012;33(1):85-95.
- 37 doi:10.1016/j.ridd.2011.08.023

22.	Kelders SM, Kok RN, Ossebaard HC, Van Gemert-Pijnen JEWC. Persuasive
	system design does matter: a systematic review of adherence to web-based
	interventions. J Med Internet Res. 2012;14(6):e152-e152. doi:10.2196/jmir.2104

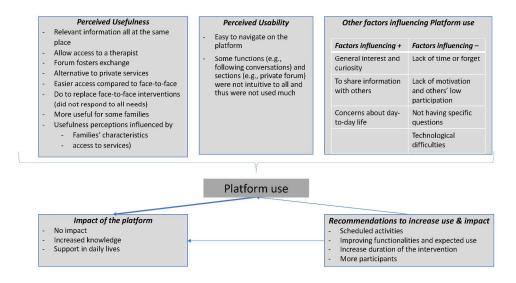
- 23. Wilson BN, Neil K, Kamps PH, Babcock S. Awareness and knowledge of developmental co-ordination disorder among physicians, teachers and parents. *Child Care Health Dev.* 2013;39(2):296-300. doi:10.1111/j.1365-2214.2012.01403.x
- 24. Hurtubise K, Pratte G, Rivard L, Berbari J, Héguy L, Camden C. Exploring engagement in a virtual community of practice in pediatric rehabilitation: who are non-users, lurkers, and posters? *Disabil Rehabil*. 2017;0(0):1-8. doi:10.1080/09638288.2017.1416496





Consort Flow diagram

215x279mm (300 x 300 DPI)



Interrelated themes that emerged from the interviews

338×190mm (200 × 200 DPI)

Table 1: Demographic characteristics

	Control group	Intervention group	p
	(n=13)	(n=15)	value
Child age, median y: mo	8:11	8:3	0.14 ^a
Child sex, male, n	10	12	1.00 ^b
Parent sex, female, n	13	14	1.00 ^b
Parent diploma, postsecondary, n	7	5	0.27°
Diagnostic status, medical suspicion of DCD, n	7	11	0.43 ^b
Child had other diagnosis or learning disability, n	6	7	0.98 ^c
No access to any kind of services, n	6	9	0.46 ^c
MABC-2, median percentile (range)	9 th (0.5-37)	5 th (0.5-37)	0.62 ^a
DCDQ, median (range)*	41 (24-52)	33 (21-59)	0.28 ^a

^a U-Mann Withney, ^b Fisher exact test, ^c Chi²

^{*}For DCDQ, score under 46-57 (according to the age of the children) indicate possible risk of DCD

Table 2: Platform utilization data

	Users		Intervention		Control		Group comparison	Therapist	Pl	atform manager
	Total	Median [quartiles]	Total	Median [quartiles]	Total	Median [qu	uartiles]	Total	Total	Median [quartiles]
Platform visits	72	1.5 [1.0;3.0]	49	1 [1.0;4.0]	23	2 [0.5;3.0]	0.89	33	24	2.5 [0.5;15.0]
Pages visited	343	3.5 [1.0;7.0]	309	7 [1.0;16.0]	34	3 [1.0;4.5]	0.08	242	305	16.5 [3.5;208.8]
Time spent (min)	4752	30 [10;93]	4340	60 [10;304]	412	30 [5;30]	0.20	1713	1712	106 [25.3;1152.8]
New forum topics	3	0 [0;0]	3	0 [0;0]	N/A	N/A	0.56	6	1	0
Forum responses	12	0 [0;0]	12	0 [0;1]	N/A	N/A	0.14	11	3	0
Private chat messages	3	0 [0;0]	3	0 [0;0]	N/A	N/A	0.56	17	0	0

Table 3. Post-intervention survey results (%)

	-		1	
		Intervention		
	Total		Control group	
		group		Mann-
	Median	C I	Median	
		Median		Whitney
	[quartiles]		[quartiles]	J
		[quartiles]		(p)
	(n=19)	[4	(n=9)	(F)
	(== ==)	(n=10)	(>)	
		(11 10)		
General satisfaction with the	65 [31;68]	60 [50;93]	65 [50;85]	0.84
General sanstaction with the	02 [21,00]	00 [50,55]	05 [50,05]	0.01
platform				
Usefulness for the participant	40 [28;80]	35 [11;60]	68 [38;80]	0.19
eserances for the participant	10 [20,00]	33 [11,00]	00 [30,00]	0.15
Perceived usefulness to	60 [39;80]	60 [25;80]	60 [50;80]	0.50
referred userumess to	00 [37,00]	00 [23,00]	00 [50,60]	0.50
deliver services				
deliver services	·C			
East of navigation	92 [71:02]	70 [44:02]	96 [76:04]	0.40
Ease of navigation	82 [71;92]	79 [44;92]	86 [76;94]	0.40
Duna and the Angel Africa	50 [21,(0]	44 [27.66]	(0.547.003	0.22
Propensity to use the internet	50 [31;68]	44 [27;66]	60 [47;80]	0.32
C DCD : C .:		7		
for DCD information				

Appendix 1. Study and Data Collection Procedures

Social mediaFamily doctors Letter and phone (waiting list)	Different access to the platform for the	1 month extra Full plateform access to all	
August 2016	January 2017	April 2017	June2017
	Data Collection		
MABC-2, DCD-Q, sociodemo		its and	Interview
		Online :	survey

Appendix 2. Recruitment and retention per recruitment procedures

Appendix 2. Ke							
Recruitment	Initial sample	Number of	Number of	Number of	Number of	Number of	Number of
procedures	of families	families	families	families	randomized	families who	families who
		interested and	assessed with	eligible after	families (who	logged in at	completed the
		eligible	the MABC-2	MABC-2	were given	least once on	post-
		following		evaluation	access to the	the platform	intervention
		phone			platform)		survey
		screening					
Social media	10	2	2	2	2	2	1
Family doctors	9	7	6	5	4	4	2
Hospital	91	31	20	24	21	15	1.0*
waiting list	91	31	30	24	21	15	16*
Reference							
from	2	2			0	0	
rehabilitation	2	2	2		0	0	0
center							
Word of	4	2	2		1	1	0
mouth	4	2	2	1	1	1	0
Posters	2	0	0	0	0	0	0
Total	118	44	39	33	28	22	19*

^{*}Including 4 families who had never logged into the platform.