IAACD

THE INTERNATIONAL ALLIANCE OF ACADEMIES OF CHILDHOOD DISABILITY

Global Professional Education Programme (GPEP) of the International Alliance of Academies of Childhood Disability (IAACD)

Work together, learn together, share together and help one another with knowledge and resources

Summary Report
November 2016

IAACD GPEP Sub-Committee Members

Nominated from the 3 ‘Founding Academies’:

- **AACPDM**
  - Diane Damiano
  - Mauricio Delgado
  - Peter Rosenbaum
- **AusACPDM**
  - Sarah Love
  - James Rice
- **EACD**
  - Jenny Carroll
  - Arnab Seal *(Chairperson)*

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1) INTRODUCTION

We live in an ever-shrinking world. The information technology revolution has enabled everyone – health professionals and the public alike – to access information and technology at a finger's click. This advance has made it possible for us to dream of a world where children with disabilities, their families and the professionals working with them have access to the right information, knowledge and training at the right time anywhere in the world.

The International Alliance of Academies of Childhood Disability (IAACD) has taken its roots from this philosophy and possibility. In January 2014 a group of interested professionals from the American Academy for Cerebral Palsy and Developmental Medicine (AACPDM), the European Academy of Childhood Disability (EACD) and the Australasian Academy (Aus ACPDM) shared the vision to create a global forum of Academies, building a partnership to include both well-established academies of childhood disability with fledgling and nascent academies, in order to foster and support each other's development. The two initial activities focused on fostering collaborative networks and promoting global teaching and training. The broader global vision is involvement not only of professionals in this knowledge exchange, but of children, parents, families and communities at large The IAACD firmly believes that the aforementioned vision will not be possible without the active participation of all these groups.

One of the first tasks agreed to and implemented by the Steering Group of the IAACD was creation of two sub-groups who were entrusted with the task of implementing the vision: the Global Professional Education Programme (GPEP) sub-group and the Best Practice sub-group. The primary goal of GPEP has been to evolve a sustainable strategy to make this vision a long-term reality. The GPEP's first tasks were to develop (i) a web survey to identify existing collaborations and training needs (see report below) and (ii) a collaborative workshop of interested people from all corners of the world at the first IAACD conference in Stockholm (2016), to discuss, share and build on the survey data. The Best Practice sub-group is tasked with producing guidelines and recommendations based on best current evidence and fostering collaborative research.

The GPEP sub-group is taking the next few steps based on the survey results and other feedback received. Initial tasks will involve (i) setting up and archiving good quality material for informing, teaching and training – material that would be free to all users; (ii) starting to set up regional faculty across the globe who can develop appropriate materials (linguistically and culturally relevant) and deliver training locally. Our survey suggests that there are many of you who would be willing volunteers for this. As always, money seemingly is a challenge, but we believe that with the enthusiasm we have seen, together we will be able to achieve this dream.

2) PURPOSE OF THE INITIATIVE

a. Help promote a common global standard of knowledge, training and multi-disciplinary practise, with an aim to improve the life chances and participation of disabled children and young people in their communities.

b. Develop and maintain a core curriculum for health professional training in child disability.

c. Encourage measures to make the educational material easily accessible and locally available.

d. Promote and facilitate development of educational faculty to disseminate training in child disability. Foster local/regional networks and international partnerships to disseminate training in order to implement best practice and promote multi-disciplinary working in child disability.

e. Define and monitor underpinning IAACD governance, ethical standards and principles of curriculum development and dissemination of training.

f. Present an annual report to the Executive Committee and Member Academies.

3) THE VISION

The GPEP subcommittee developed a vision for our shared goals that included:

- Creating a permissive environment of equal global partners.
- Ensuring that we reach everyone who is interested to be involved.
- Ensuring that everyone interested has a say.
- Having a needs-based approach, locally driven rather than prescribed from the top.

Philosophy

Philosophy of care and services promoted by the three academies supporting these developments:

- Evidence-informed practice – using the best available evidence to guide decision-making at both the individual and programme levels

- Use of ICF concepts: focus on child and family functioning grounded in the WHO's biopsychosocial framework
- Promoting and practicing a family-centred shared care model
- Life course approach that considers the long-term impacts of all services across the lifespan.
- Moving beyond a 'fixing' model of intensive therapy to focus on what people 'can do' and want to do.
- Promote trans-disciplinary non-hierarchical care models
- Endeavour to speak the same language wherever in the world we are!

4) SURVEY

The GPEP understands that there is much valuable education and training already taking place globally and members are keen to acknowledge and work with global partners already in the field. In order to gather information and develop a baseline of what was already happening across the globe a survey was conducted by the GPEP in Spring 2016 entitled:

"What are your training needs and what training do you provide?"

To reach as many people as possible this survey was conducted online and links to it were disseminated as follows:

- Email to members of EACD, AACPDM, AusACPDM with request to forward to other interested groups.
- Contacts with known international partners and academies
- Postings in various international forums
- Responses received from March to May 2016
- 946 responses from all over the world

Questionnaire in 2 parts

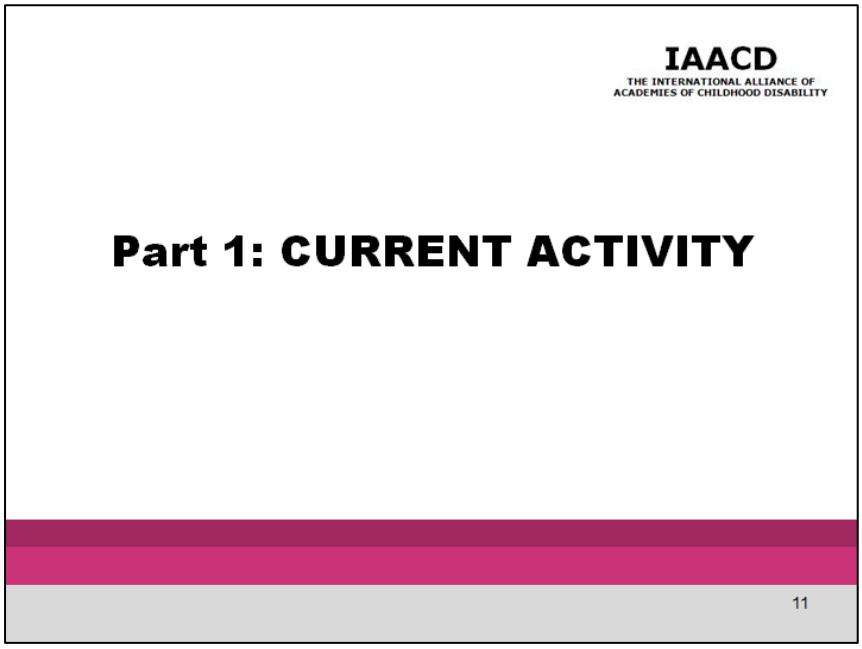
Part 1 asked about ***training in developmental disabilities already being provided.***

Part 2 about what ***training in developmental disabilities professionals would like to receive***.

The objectives of the survey were to:

- map current training activities;
- assess demands/perceived needs and priorities for training;
- assess what types of training materials (content and format) are needed and useful; and
- consider potential partnerships.

5) SURVEY RESULTS (PART 1) – TRAINING PROVIDED



Q1 Do you deliver training in an international context?

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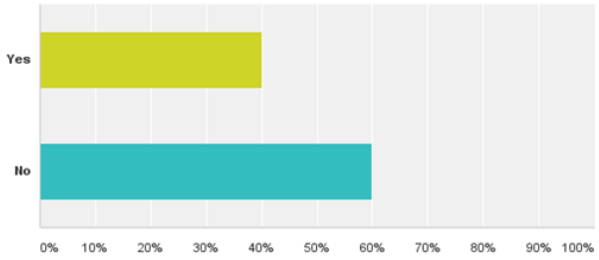

368 respondents answered yes to this question.

Q2, Q3, Q4 Training delivered: Who and Where?

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- There were 111 distinct organisations
- Delivering training directly in 29 languages!
- These activities are happening in 94 countries! – likely to be many more!

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Question 6 –Who are the learners?

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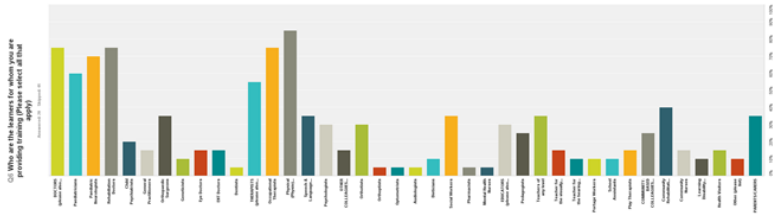

***Please refer to Appendix 1 at the end of this report**

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Question 6: Who are the learners? Summary

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- The data show that training is primarily aimed at therapists, then doctors, and then parents and carers
- There is training provided for 36 professions as well as parents and carers

Question 7 Numbers of people currently trained annually?

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- Approximately 14,000 people have received training per year.
- Wide range from 1 to 1500 people receiving training from groups

Question 14 Please share any more information/experience (training providers)

THEME I: Cultural sensitivity, appropriateness, adapted AND inexpensive

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- Materials need to be culturally appropriate, with training, pitched at the right level, and at a cost that is affordable
- Need for good quality linguistic translation if materials are in English
- Outcome measures are usually validated for Western societies; hence there is a need for 'appropriate' measures addressing relevant local questions/issues

Q 14, THEME I: Cultural sensitivity, appropriateness, adapted AND inexpensive (continued)

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- Challenge of cultural contexts – hence *cultural* as well as *linguistic* translations and adaptations
- Challenge of people understanding ideas such as Family Centred Services, Goal setting, Transdisciplinary model
- CBR: Material has to be suitable for both health professionals and non-expert health facilitators who play a big role in many communities

Q 14, THEME II: Challenges for people to attend continuing education

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- Challenge of costs: loss of earning to attend training
- Time constraints to have Continuing Education
- Political will: need to have the 'higher-ups' value this
- The challenge of follow-through/application of new ideas You teach, but no change/uptake in practice
- Need to identify benefits to local population and individuals – otherwise changes are not adopted

Q 14, THEME III: Who should be offered opportunities to learn?

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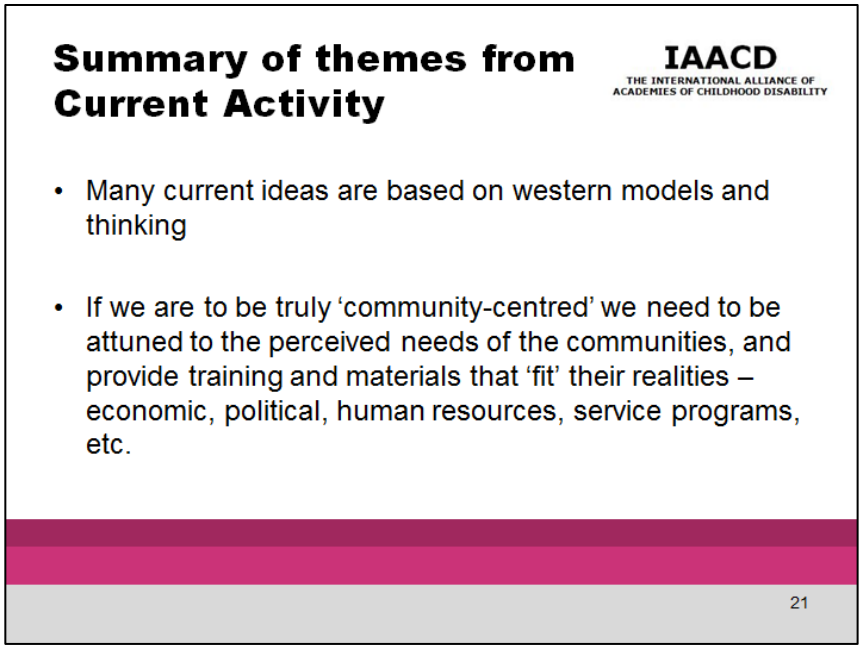
- Need for inclusive education – to involve all relevant community people
- Train the local providers, train-the-trainer model (often called Knowledge Brokers)
- There are many examples of collaborations and examples of local courses



6) SURVEY RESULTS (PART 2) – PERCEIVED DEMAND FOR TRAINING

Question 16
Would you or your group make use of an education programme?

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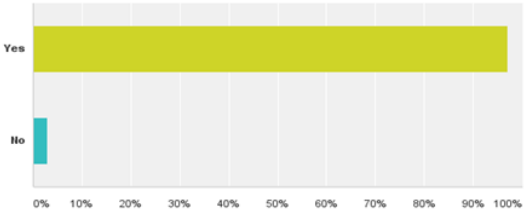

Yes 358
No 11

Question 17 Which of the professions below are in your group/community and would like to access training?

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- 40 different professions plus parents and carers wanting to access training.
- Similar pattern to the training provided (Part 1), with **therapists** most wanting training, then **doctors** and then **parents.**

Question 19 Which languages would need to be available?

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- 40 languages requested. Vast majority was English.
- Hence the need for local 'champions' (Knowledge Brokers) to lead change in their own communities
- Implications for what – and how – IAACD acts.

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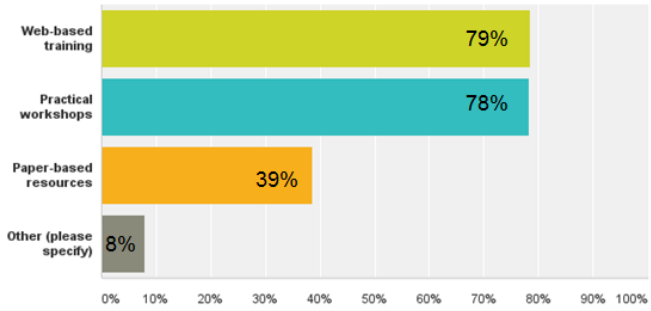
What format of training material would be most useful

Answered: 363 Skipped: 563



Q 18 & 20, What are people's perceived training priorities?

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Nearly 600 responses outlining training needs and priorities. We have analysed and interpreted the themes under

- Condition specific priorities
- Content priorities
- Process priorities

Q 18 & 20, What are people's perceived training priorities?

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- **Priority conditions listed in this order:**
  - Cerebral Palsy
  - Autistic Spectrum Disorder
  - Neuromuscular
  - ADHD
  - Sensory Impairments

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Q 18 & 20, Our interpretations

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CONTENT **issues that require specific materials and resources, which can be broken into (i) material that could be (is) available already, and (ii) content that may be more child-specific**

- **HOW TO…**
  - **Therapy-related training Needs:** New treatments, CIMT/BIMP, strengthening, fitness, task-specific training, gait training, general movements, sensory integration, technology, splinting, access/adaptations, early interventions, NDT/Bobath, activities of daily living, prevention of secondary complications, communication and dysphagia.

Additional content themes

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- **CHILD ISSUES:**
  Basic concepts, typical and atypical development
- **PARENT and TEACHER COMMUNICATION ISSUES**
  Parent training/coaching, teacher training, parent support, communicating with caregivers
- **ADVOCACY ISSUES**:
  Reducing stigma, inclusion, political will/priority and social awareness, community education, child registries

Additional content themes

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- **Assessment tools and functional Scales:**
  Need for tools that are simple, easy to use, locally adaptable, will be valid for local populations
- **Genetics, new genetics, neurogenetics and genetic counselling**
- **Other topics**: Palliative end-of-life care, dental care, bladder/bowel, IT solutions, leadership training, sleep issues, graduate and post-graduate programmes particularly in SALT and OT

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Q 18 & 20, Our interpretations

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PROCESS issues with which people want help

- **Themes related to improving participation and independence, understanding underlying concepts and tools to deliver this in practice.** Examples: ICF/participation, goal-setting, outcome measures, family-centred service, quality of life, ADLs, Early Intervention, Transdisciplinary working.
- **Critical appraisal, research methods, statistics, how to embed research in to clinical practice**

Additional process themes

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PROCESS issues with which people want help (by frequency)

- Spasticity management, dystonia management, movement disorders
- Orthopaedic and surgical interventions
  Dysphagia/aspiration/oromotor dysfunction and nutrition
- Pain
- Drooling
- Behaviour, mental health, challenging behaviour

Additional process themes

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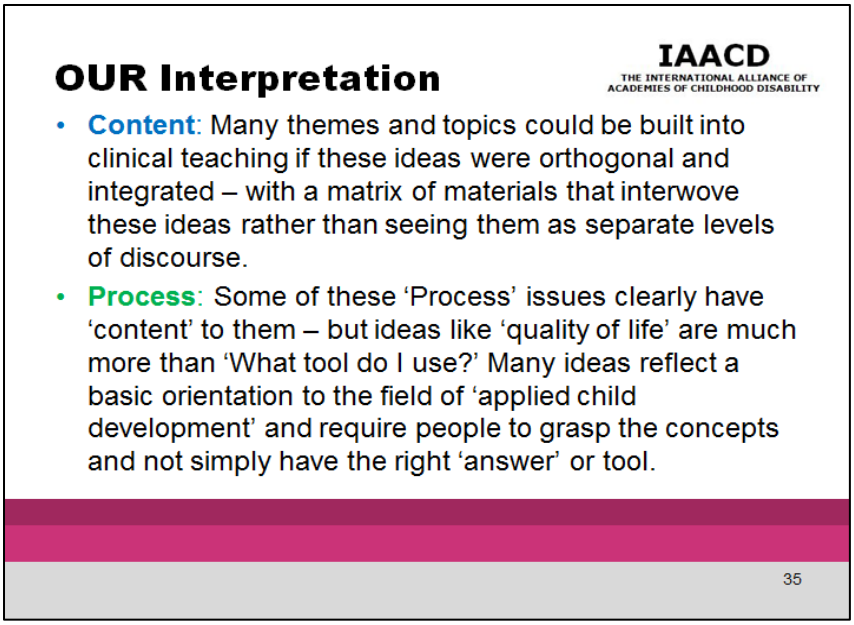
- **Transition to adult life, independence, supported living, employment, future planning, lifecourse approach to future planning, life skills**
- **Prevention of disability** and Prevention of Secondary disability
- **Community Based Rehabilitation Approaches**: need for materials that can be used by non-health community facilitators who often have minimal education (? IT solutions, podcasts audio/video)



7) CONCLUSIONS

Discussions at GPEP meeting in Stockholm

Summary of discussion in GPEP Session at Stockholm 2016:

Participants discussed in groups the themes outlined above i.e. Educational resources, Local contexts and Challenges; the following is a summary of suggestions from participants

- AACPDM, AusACPDM and EACD all have separate websites. A centralised website was discussed with most participants being in favour of a centralised IAACD website with a two-way link to local organisational networks. There was a proposal of creating a network of reliable/trusted organisational websites/groups (e.g. *CanChild*), which would allow clinicians to search and access relevant good quality material.

- Create a bank of IAACD-approved training materials with a date of when last updated and links to evidence.

- Centralised website would provide access to training material, condition-specific information, 'how to' information. It needs to allow 'search' filter functionality to locate the right material, and be well curated to both organise material and weed out untrustworthy material.

- Cost: the material to be available free of cost and in a printable format. Need for additional funding to support whole initiative.

- Ability to request paper copy: There was recognition that in many areas access to the web was difficult and there would need to be an ability to request a paper copy. An added bonus would be to request a search or information on a particular issue.

- Copyright: the central archive would need to consider copyright issues.

- Library: this was deemed expensive to set up and maintain.

- Quality review by volunteers: the quality of information approved for use on any particular topic would be done by requesting volunteer individuals, groups and/or organisations. The volunteers would be acknowledged by the IAACD for their contribution. May need additional funding for sustainability.

- Peer review: rotate peer review groups to ensure that the process is sustainable. Need a system to allow 'Add changes' if other reviewers/users have access to better/more comprehensive/more up-to-date resources i.e. merging resources on same topic. Would need to be a peer-reviewed non-controversial system.

- User reviews: have a 'user review' function so that users can leave a review of the material and its functionality. This would be helpful for subsequent users (Tripadvisor model).

- Consider having 'levels' for each topic e.g. for medics, therapists, community-based workers, parents or everything written in clear jargon free language.

- Needs to reflect multicultural background: cultural translations would be needed by local users to make any training material relevant to the local context.

- Local adaptations: any training material created should have the functionality of notes/adaptations by local trainers. This may need some form of remote advice being available for local trainers.

- Use technology to solve problems of archiving and updating.

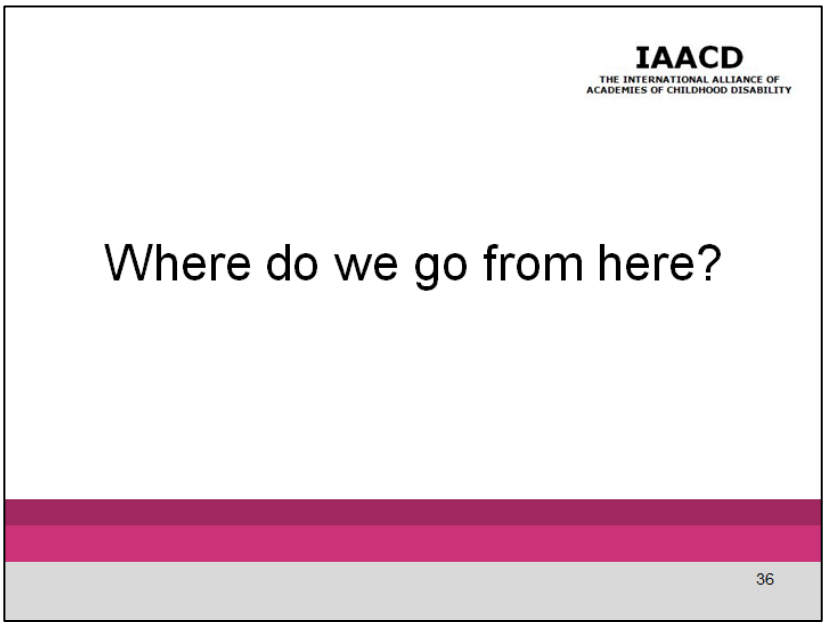
- Consider technologies to help disseminate e.g. Apps.

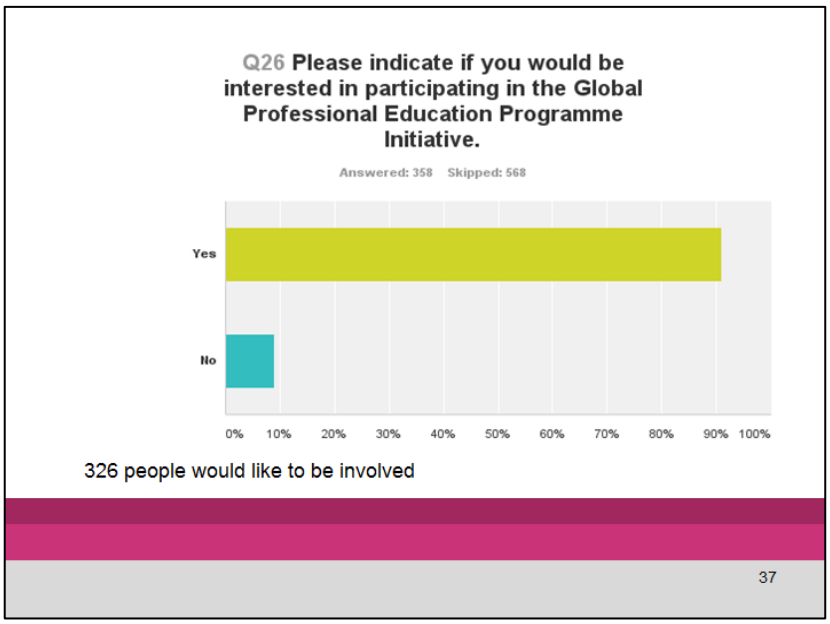
- Need to create local/regional courses by collaboration.

- Consider models of Summer Schools/Winter Schools to allow opportunity for training key individuals who can lead delivery of local training. Consider alternative models of linking knowledge brokers to knowledge seekers e.g. Tinder model

- Consider web-based training material using webinars, videos, YouTube clips, lecture videos etc.
- Include trainers from all parts of the world to deliver training.

8) WHERE DO WE GO FROM HERE?





Global Professional Education Programme (GPEP)

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Educational resources

- 'Library' of educational resources/material: How do we vet the validity, academic standard and quality control? How do we make sure it will stand up to any scrutiny?
- Do we need a IAACD website for this work – or build IAACD sub-sites into existing sites?
- Need for multiple languages and translations. Need for 'cultural translations' for relevance. Need for resources that can be locally adaptable for any context. How can we achieve this?

Global Professional Education Programme (GPEP) *Local Contexts*

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- How do we maintain relevance across Low, Medium, High resource settings?
- Trans-disciplinary non-hierarchical models: how do we promote?
- Need local/regional champions (honest 'Knowledge brokers' with no ulterior motives). How do we find them and how do we agree who?
- Need political will and backing. How?
- Ethical standards: how do we agree these?

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Global Professional Education Programme (GPEP)

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Other Challenges

- Funding: some thoughts please!
- Time…everyone's!
- Ulterior motive of gain e.g. financial, political: we must guard against this happening and interfering with what many of us see as part of our leadership responsibility to the 'world' of childhood disability.
- Technology: we need low cost but effective tech
- Imperialistic attitudes: we must protect against the risk of adopting what is believed, preached and even valid in resource rich settings

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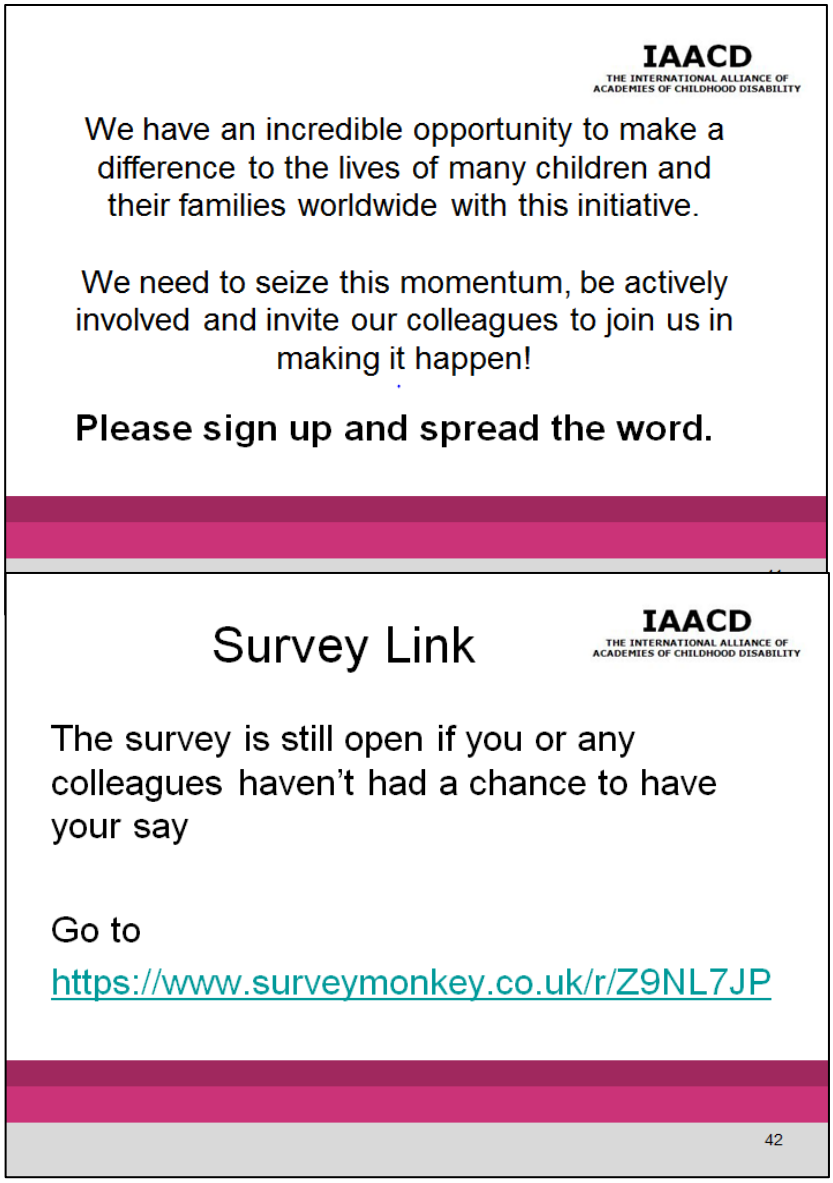


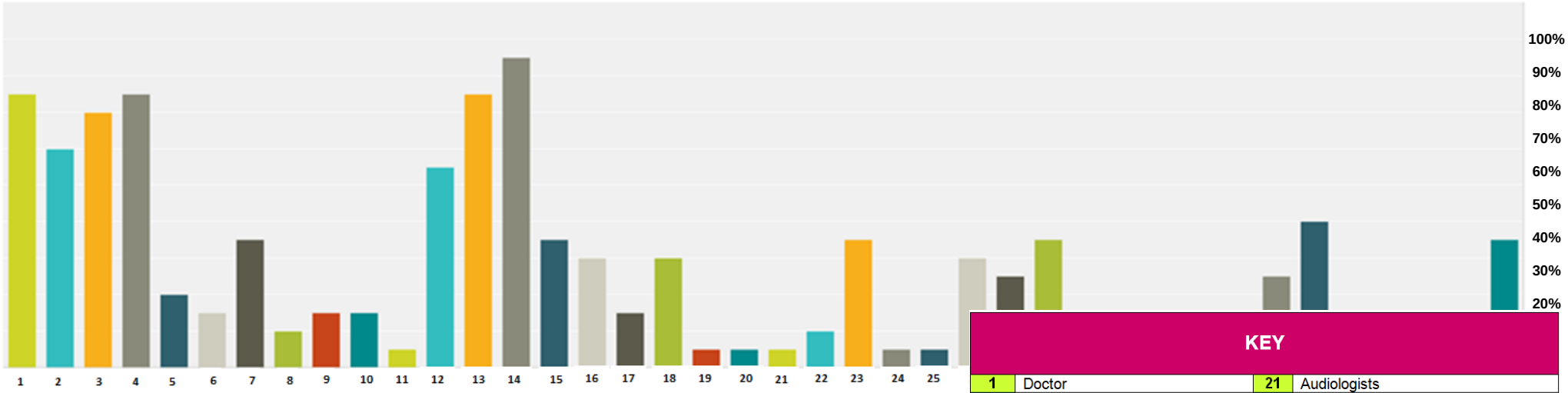
9) SUMMARY

We have an incredible opportunity to make difference to the lives of many patients with childhood onset disabilities and their families worldwide with this initiative. We need to seize this momentum, be actively involved and invite our colleagues to join us in making it happen!

Please sign up and spread the word!

APPENDIX 1

Q6 – Who are the learners for whom you are providing training?



KEY			
1	Doctor	21	Audiologists
2	Paediatricians	22	Dieticians
3	Paediatric Neurologists	23	Social Workers
4	Rehabilitation Doctors	24	Pharmacists
5	Child Psychiatrists	25	Mental Health Nurses
6	General Practitioners	26	Educators
7	Orthopaedic Surgeons	27	Pedagogists
8	Geneticists	28	Teachers of any Level
9	Eye Doctors	29	Teacher for the Visually Impaired
10	ENT Doctors	30	Teacher for the Hearing impaired
11	Dentists	31	Portage Workers
12	Therapists	32	School Assistants
13	Occupational Therapists	33	Play Therapists
14	Physical (Physiotherapists)	34	Community Based Colleagues
15	Speech &Language Therapists	35	Community Rehabilitation Worker
16	Psychologists	36	Community Nurses
17	Other Colleagues	37	Learning Disability Nurses
18	Orthotists	38	Health Visitors
19	Orthoptists	39	Other
20	Optometrists	40	Parents/Carers