# Wege zur Inklusion
# Pathways to Inclusion

## Leicht Lesen Information über den Kongress
## Easy To Read Information about the Congress

4. IASSIDD Europa Kongress vom 14. bis 18. Juli 2014 an der Universität Wien

4th IASSIDD Europe Congress from July 14th to July 18th at the University of Vienna in Austria

Law
and
Liberty

Health

Education

Inclusion

Participation
across
the Lifespan

Living
in the Community

Work
and
Employment

universität
wien

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lebenshilfe
ÖSTERREICH

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# Was soll ich über den Kongress wissen?

Wenn viele Menschen zusammenkommen, die sich mit einem Thema befassen, heißt das Kongress. Der Kongress ist eine große Veranstaltung.

Die Veranstaltung heißt Europa-Kongress, weil Menschen aus vielen europäischen Ländern nach Wien kommen.

Menschen mit Behinderung und ohne Behinderung sind zum Kongress eingeladen.

Sie reden darüber, was Forscherinnen und Forscher über Menschen mit Lernschwierigkeiten herausgefunden haben. Sie sprechen auch über die UN-Konvention. Das ist ein Dokument über die Rechte von Menschen mit Behinderung auf der ganzen Welt.

Menschen mit Lernschwierigkeiten reden genauso mit wie andere Expertinnen und Experten. Sie alle sprechen über das Thema Inklusion.

Der Europa-Kongress findet in der Universität Wien statt.

Die Universität liegt mitten in der Stadt Wien.

Dort kann man auch andere schöne, alte Gebäude besichtigen.

Wer will, kann in den Pausen in der Stadt bummeln.

Der Kongress wird von IASSIDD veranstaltet. Das ist eine Vereinigung, die es in vielen Ländern gibt. IASSIDD beschäftigt sich mit dem Thema Lernschwierigkeiten.

IASSIDD veranstaltet den Europa-Kongress gemeinsam mit der Universität Wien und der Lebenshilfe Österreich.

# What should I know about the congress?

When many people meet and discuss an important topic, it is called a congress. A congress is a big event.

This congress is called Europe-Congress because people from all over Europe are coming to Vienna.

People with disabilities and people without disabilities are invited.

They talk about, what scientists have found out about people with Learning Disabilities. They also talk about the UN-convention. This is a document about the rights of people with ID all over the world.

The talks will be held by people with ID and also other experts. They speak all about the topic Inclusion.

The congress takes place at the University of Vienna.

The University is located in the center of Vienna.

There are also many other beautiful, old buildings.

If you want, you can take a walk through the city in the breaks.

The congress is organized by IASSIDD. This is an organization that you can find in many countries. IASSIDD focuses on the topic of Learning Disabilities.

It is organizing the congress together with the University of Vienna and the Lebenshilfe Österreich.

# Was sind die wichtigsten Informationen?

**Anmeldung:**

Die Registratur befindet sich in der Aula der Universität Wien. Das ist der große Raum hinter dem Haupteingang.

Dort müssen Sie sich anmelden.

Danach bekommen Sie eine Kongresstasche und ein Namensschild. Bitte tragen Sie das Schild so lange Sie sich am Kongress befinden.

Wenn Sie während des Kongresses Fragen haben, finden Sie bei der Registratur Hilfe.

**Kongresssprache:**

Die meisten Vorträge werden auf Englisch gehalten.

Die Workshops sind entweder auf Englisch oder auf Deutsch.

Einige Vorträge werden in leichter Sprache gehalten. Diese werden auch auf Deutsch und Englisch übersetzt. Sie finden diese Vorträge unter dem Titel „Inklusions Track" in diesem Programm.

**Internet:**

Ein kostenfreier Internetzugang ist möglich. In der Kongresstasche ist ein Zettel mit den Zugangsdaten und einer Anleitung.

**Notfall:**

Der Krankenwagen kommt, wenn Sie 144 anrufen.

Die Polizei kommt, wenn Sie 133 anrufen.

Die Feuerwehr kommt, wenn Sie 122 anrufen.

Das nächste Krankenhaus ist das AKH Wien. Das ist die Adresse:

AKH Wien

Währinger Gürtel 18-20

1090 Wien

Tel.: 01 404000

# What is the most important information?

**Registration:**

The registration is located in the assembly hall of the University of Vienna. That is the big hall behind the main entrance.

There you can register. You have to tell the people there that you are here, before you can attend the congress.

Then you get a congress bag and a name badge. Please wear the name badge as long as you are attending the congress.

If you have got any questions, the people at the registration will help you.

**Language:**

Most presentations are in English.

Workshops are either in English or in German language.

Some presentations will also be held in Easy Language. These presentations and talks will be translated to German and English. You will find them in this program in the section "Inclusion Track"

**Internet:**

You have free access to wireless internet. You can find further instructions and the Log-In data in you congress bag.

**In case of emergencies:**

You can call the ambulance: 144

You can reach the police: 133

If there is fire call: 122

The closest hospital is the AKH Vienna. This is the address:

AKH Wien

Währinger Gürtel 18-20

1090 Wien

+34(0)1 404000

# Was ist der „Inklusions Track“?

Das Thema des Kongresses heißt „Wege der Inklusion“.

Inklusion heißt: Alle Menschen können mitmachen und dürfen dabei sein.

Es wird mit Selbstvertretern über Intellektuelle Behinderung (IB) gesprochen.

Wer Unterstützung braucht, um dabei zu sein, bekommt sie. Das wird auch Thema des „Inklusions Track“ sein.

Bei dem Inklusions Track gibt es verschiedene Programme.

1. Keynote Nachbesprechung:
   Die Keynote-Vortragenden sind bekannte Menschen, die sich mit dem Thema IB beschäftigen. Jeden Tag gibt es zwei Keynote Vorträge. Im Inklusions Track erklären die Keynote-Vortragenden ihren Vortrag. Das machen sie in leichter Sprache damit es alle verstehen.

2. Vorträge
   In den Vorträgen erklären die Autoren ein Thema in leichter Sprache. In manchen Vorträgen wird auch ein Film gezeigt. Die Vorträge werden von diesen Themen handeln:
   - „Unterstützte Entscheidungsfindung“
   - „Inklusion am Arbeitsplatz“
   - „In der Gesellschaft integriert leben“

3. Round Table
   Bei einem Round Table setzen sich Personen gemeinsam an einen Tisch und besprechen ein wichtiges Thema. Oft kommen diese Personen aus verschiedenen Bereichen und können so neue Argumente kennen lernen. Bei einigen Round Tables werden auch Selbstvertreter mitdiskutieren. Diese Diskussionen kann man sich anhören und auch selbst mitdiskutieren.

# What is the “Inclusion Track”?

The congress topic is „Pathways to Inclusion“.

Inclusion means that everyone may participate.

People with intellectual disabilities (ID) and people without ID will talk about Disabilities.

Everyone who needs support to participate will get it. This will be a topic of the “Inclusion Track”.

There will be different programs in the Inclusion Track:

1. Keynote debriefing:
   The Keynote-Speakers are well-known people, who are concerned about the topic of ID. There are two keynotes every day. The Keynote-Speakers explain their talks in the Inclusion Track in Easy Language. This way everyone can understand what they are saying.

2. Presentations
   These presentations are held in Easy Language. There will also be films during some of these presentations. The presentations are about these topics:
   - „Supported Decision Making“
   - „Inclusion in the Workpalce“
   - „Community based Living“

3. Round Table
   For a Round Table people gather around a table and discuss an important topic. Very often these people have different professions. This way they can learn from each other. There will also be self-advocates at these Round Tables. You can listen to these discussions and contribute your views.

# Welche Abkürzungen gibt es im Programmheft?

Das sind die anderen Themen im Kongress:

Bei **EDU** ist Bildung das Thema.

Bei **HEALTH** geht es um das Thema Gesundheit.

Bei **LAW** geht es um das Gesetz. Besonders geht es um Gesetze die Personen mit Beeinträchtigung betreffen.

Bei **LIV** ist das Leben in der Gemeinschaft Thema.

Bei **PART** ist die Inklusion von jungen Menschen bis hin zu älteren Menschen das Thema.

Bei **W&E** geht es um Arbeit und Bildung.

Das sind andere Abkürzungen:

Bei **D** gibt es Vorführungen wie zum Beispiel einen Film.

**K** ist die Abkürzung für eine Keynote Nachbesprechung.

**RT** ist die Abkürzung für einen Round Table.

**S** ist die Abkürzung für ein Symposium.

**I** ist die Abkürzung für einen Inklusiven Vortrag.

**I RT** ist die Abkürzung für einen Inklusiven Round Table.

## What do the shortcuts in the program mean?

These are the other congress topics:

**EDU** is about Education.

**HEALTH** is about health related topics.

**LAW** is about the rights of people with ID.

**LIV** is about living in a community.

**PART** is about the participation in the society from young age to old age.

**W&E** is about work and education.

These are other abbreviations:

**D** means there will be some kind of demonstration like a film.

**K** is the abbreviation for a Keynote-debriefing.

**RT** is the abbreviation for a Round Table.

**S** is the abbreviation for a Symposium.

**I** means that this is an inclusive presentation in Easy Language.

**I RT** means that this is an inclusive Round Table in Easy Language

## Unterstützung bei Entscheidungen: nur für Ministerpräsidenten?

M. Schulze

Das Abkommen über die Rechte von Menschen mit Beeinträchtigungen gilt in vielen Ländern. Menschenrechte müssen auch für Menschen mit Beeinträchtigung gelten. Menschen mit Beeinträchtigungen sind mehr als ihre Beeinträchtigung. Menschen sollten die Person sehen, nicht die Beeinträchtigung. Menschen mit Beeinträchtigung müssen nicht geheilt werden. Die Leute müssen ihre Einstellung gegenüber Menschen mit Beeinträchtigungen ändern.

Der Beitrag von Menschen mit Beeinträchtigung ist wichtig. Menschen mit Beeinträchtigung können viel beitragen und man muss ihnen die Gelegenheit dazu geben. Das Abkommen über die Rechte von Personen mit Beeinträchtigung wurde auch durch Menschen gemacht, die selbst eine Beeinträchtigung haben. Menschen mit Beeinträchtigung mitmachen zu lassen, macht es einfacher Personen mitmachen zu lassen, die ausgeschlossen sind. Zum Beispiel: Obdachlose.

Menschen mit Beeinträchtigung miteinzubeziehen ist einfach. Oft sind Menschen und Vereine nur nicht daran gewohnt. Menschen denken, sie wissen, was gut ist für Personen mit Beeinträchtigung. Die Leute versuchen oft, Menschen mit Beeinträchtigung zu beschützen, aber das ist oft nicht das Beste für sie. Die Leute müssen lernen dass Menschen mit Beeinträchtigung selbst wissen, was für sie am besten ist.

Die Leute müssen die Entscheidungen von Menschen mit Beeinträchtigung akzeptieren. Entscheidungen können auch falsch sein. Jeder macht Fehler. Jeder lernt von Fehlern. Fehler machen ist wichtig. Wenn jemand zu sehr beschützt wird, ist es nicht einfach, Fehler zu machen.

Jeder hat das Recht, für sich selbst zu entscheiden. Es ist wichtig, Entscheidungen zu treffen. Manchmal braucht man Unterstützung wenn man Entscheidungen trifft. Ein paar Entscheidungen sind nicht einfach. Manchmal braucht man Hilfe dabei. Jeder hat das Recht, Unterstützung zu bekommen beim Entscheiden.

Viele Menschen brauchen Hilfe beim Entscheiden. Zum Beispiel hat der Ministerpräsident viel Hilfe wenn er Entscheidungen trifft. Es ist eine gute Idee, diese Unterstützung zu haben. Ist diese Unterstützung für den Ministerpräsident anders als die Unterstützung die Menschen mit Beeinträchtigung bekommen?

Es gibt wichtige Entscheidungen die der Ministerpräsident machen muss. Viele sind schwierig. Die Unterstützung beim Entscheidungen treffen ist nicht anders für Menschen mit Beeinträchtigung. Es braucht nur ein bisschen mehr Anstrengung und Zeit.

Einbindung bedeutet auch, dass wir die Unterstützung Menschen mit Beeinträchtigung mit der Unterstützung für andere vergleichen. Das was Menschen mit Beeinträchtigung brauchen ist nicht „anders“ oder „besonders“.

## Supported decision-making: for prime ministers only?

M. Schulze

The Convention on the Rights of Persons with Disabilities is in force in many countries. Human rights have to be applied to persons with disabilities. There is more to persons with disabilities than their impairment. People should focus on the person. Persons with disabilities do not need to be fixed. People have to fix their attitudes towards persons with disabilities.

The contribution of persons with disabilities is essential. Persons with disabilities can contribute very well. They have to be given an opportunity to do so. The Convention on the Rights of Persons with Disabilities was also negotiated by self-advocates. Involving persons with disabilities makes it easier to include other people who are excluded. For example: homeless people.

Including persons with disabilities is easy. Often people and institutions are not used to that. People think they know what is good for persons with disabilities. People often cotton-wool persons with disabilities. People mean very well. But that is not always the best for persons with disabilities. People have to learn that persons with disabilities know themselves what is best for them.

People have to accept the decisions made by persons with disabilities. Decisions can lead to mistakes. Everyone makes mistakes. Everyone learns from mistakes. Making a mistake is important. When one is over protected it is not so easy to make mistakes.

Everyone has the right to make decisions for themselves. It is important to actually make those decisions. Sometimes one needs assistance when making decisions. Some decisions are complicated. Then one might need more assistance. Everyone has the right to have assistance in decision-making.

A lot of people rely on support in decision-making. For example, the prime minister has a lot of support when he makes decisions. It is a good idea to have such support. Is the support to the prime minister different to that for a person with intellectual impairment?

There are important decisions for the prime minister to make. Some are complex. The process of support in decision-making is no different for persons with disabilities. It takes a bit more effort and time.

Inclusion also means that we compare the support of "chronically normal" persons and of persons with disabilities.  The needs of persons with disabilities are not that "different" or "special."

# Ungleichheit, Bildung & Beeinträchtigung. Die Rolle von inkludierenden Strategien beim Übergang von Schule zur Arbeit.

L. Pfahl

Ungleichheit ist ein wichtiges Thema in der Forschung. Ungleichheit bedeutet, dass manche Menschen weniger Geld, Dinge oder Möglichkeiten haben als andere.

Studien über Beeinträchtigung können etwas aus den Gesprächen über Ungleichheit lernen. In diesem Vortrag werde ich zuerst fragen: Was ist Ungleichheit?

Ich werde darüber sprechen, was Menschen über Ungleichheit denken.

Dann werde ich fragen: warum ist Beeinträchtigung eine Ungleichheit?

Ist Beeinträchtigung der Grund für Ungleichheit oder ist Beeinträchtigung eine Folge der Ungleichheit.

Oder ist es einfach so, dass Menschen mit Beeinträchtigung nicht gleich wie andere sein können?

Beeinträchtigung bedeutet in verschiedenen Ländern verschiedene Dinge und führt dabei zu verschiedenen Ungleichheiten.

Um zu verstehen warum Menschen mit Beeinträchtigung nicht gleich wie andere sind, müssen wir etwas über diese Länder lernen.

In Europa glaubt man, dass Menschen gleich sind, wenn sie arbeiten können.

Als drittes werde ich fragen: Was kann die Politik von den Kämpfen gegen Ungleichheit von Menschen mit Beeinträchtigung lernen?

Der Kampf für gleiche Bildung und Arbeit ist wichtig für die Einbindung von Menschen mit Beeinträchtigung in die Gesellschaft.

# Inequality, Education & Disability. The Role of Inclusive Policies in School-to-Work Transitions

L. Pfahl

Inequality is an important topic of social research and educational research. Inequality means that some people have less money, things or chances than other people.

Disability studies can profit from the discussion of inequality.

In my lecture, I will ask first: What is inequality?

I will talk about what people think about inequality.

Second, I will ask: in what way disability is a form of inequality?

Disability is a cause for not being equal or disability is a consequence of inequality.

Or it just seems natural that disabled people cannot be equal to others.

In different countries disabilities mean different things and lead to inequalities in different ways.

To understand how disability prevents people from being equal we need to study these countries.

In all european countries people belief people are equal when they are able to work.

Thirdly, I will ask: what can disability policy learn from struggles against inequality?

The fight for equal education and work is important for the inclusion of disabled people.

## Erschließen der Bedingungen erfolgreichen Alterns: der Beitrag der intellektuellen Beeinträchtigung zur irischen Längsschnittstudie über das Altern

M. McCarron

Hintergrund und Ziele: Menschen mit intellektueller Beeinträchtigung werden immer älter. Sie bleiben lange gesund und genießen das Leben.

Im Vergleich zum Rest der Bevölkerung, haben Menschen mit intellektueller Beeinträchtigung aber öfter einen ungesunden Lebensstil. Sie erkennen ihre Gesundheitsprobleme oft nicht.

Wir alle, Menschen mit und ohne intellektueller Beeinträchtigung, müssen Personen mit intellektueller Beeinträchtigung die Möglichkeit zu einem gesunden Lebensstil und Altern geben.

Methoden: Es gab eine große Studie in Irland, genannt IDS-TILDA.

Diese Studie hat das Altern von Menschen mit intellektueller Beeinträchtigung mit dem Altern von Menschen ohne intellektuelle Beeinträchtigung verglichen.

Die Studie überprüfte:

- die Gesundheit
- die Unabhängigkeit
- die soziale Situation
- die ökonomische Situation
- und die Situation der Umwelt

von Menschen über 40 mit intellektueller Beeinträchtigung. Dann wurden die Ergebnisse dieser Studie mit den Ergebnissen von Menschen ohne intellektuelle Beeinträchtigung verglichen.

Man fand heraus:

- Menschen mit intellektueller Beeinträchtigung nehmen oft an sozialen Veranstaltungen teil
- Menschen mit intellektueller Beeinträchtigung geben selten an, dass sie sich Sorgen über das Alter machen oder darüber, zu wenig Geld zu haben. Sie geben auch selten an, von anderen nicht gut behandelt zu werden.
- Menschen mit intellektueller Beeinträchtigung sind nicht sehr in die Gemeinschaft eingebunden
- Menschen mit intellektueller Beeinträchtigung sind öfters krank oder haben psychische Probleme. Sie haben auch öfters Probleme mit dem Sehen als Menschen ohne intellektuelle Beeinträchtigung. Aber Menschen ohne intellektuelle Beeinträchtigung leiden öfter an Bluthochdruck als Menschen mit intellektueller Beeinträchtigung.
- Junge Menschen mit intellektueller Beeinträchtigung rauchen viel seltener Zigaretten als junge Menschen ohne intellektuelle Beeinträchtigung. Ältere Menschen mit intellektueller Beeinträchtigung aber rauchen öfter Zigaretten als ältere Menschen ohne intellektuelle Beeinträchtigung.
- Im Vergleich zum Rest der Bevölkerung haben Menschen mit Beeinträchtigung weniger Bewegung.
- Viele Menschen mit intellektueller Beeinträchtigung hatten niemals etwas geschrieben, eine SMS geschrieben, eine E-Mail geschrieben oder soziale

Netzwerke wie Facebook benutzt, um mit ihren Familien und Freunden in Kontakt zu treten.

- Viele Menschen mit intellektueller Beeinträchtigung haben Schwierigkeiten mit Straßenschildern, Gebäudeeingänge und mehr.

Diskussion: Menschen mit intellektueller Beeinträchtigung müssen in die Gesellschaft eingebunden werden. Die Ergebnisse dieser Studie aus Irland sollen helfen, die Politik und Einrichtungen so zu beeinflussen, dass diese mehr tun können für ein erfolgreiches Altern und eine gute Gesundheit von Menschen mit intellektueller Beeinträchtigung.

## Unlocking the determinants of successful ageing: the intellectual disability supplement to the Irish longitudinal study on ageing

M. McCarron

Background and Aims: People with intellectual disabilities in many countries are living longer, healthier and are enjoying life.

But, compared to the general population, people with intellectual disability more often have an unhealthy lifestyle and they often do not recognize their health problems.

We as a society are responsible for providing people with intellectual disabilities the opportunity to have a healthy lifestyle and age.

Methods: There was a large study (called IDS-TILDA) in Ireland. This Study compared ageing of people with and without an intellectual disability.

The study looked at:

- health
- independence
- social situations
- economic situations
- and environmental situations

of persons over 40 years with an intellectual disability.

Then the results of this study were compared to the results of persons without an intellectual disability.

Results:

- People with an intellectual disability often participate in many social activities

- People with an intellectual disability rarely say that they are preoccupied about getting older, or not having enough money or that they are not treated well by others.
- People with an intellectual disability are not very involved in their communities
- People with an intellectual disability have diseases like diabetes or difficult emotional and psychological situations more often than others. They also have more problems with the eyesight than other people. However, non-disabled people more often have high blood pressure than people with an intellectual disability.
- Young people with an intellectual disability are smoking much less than people without, but older people with intellectual disability are smoking more often than people without.
- Compared with the general population, less people with intellectual disability do exercise
- Many persons with intellectual disability have never written a text or used social media like Facebook to contact their friends and family
- Many people with intellectual disabilities have difficulties with street signage, building entries and so on.

Discussion: People with intellectual disability must be included in society. The results of the study in Ireland should help to influence policy and service so that they can plan on a successfully ageing and healthy disabled population.

## Institution, Haus oder etwas dazwischen: der aktuelle Stand der Deinstitutionalisierung in Zentral- und Osteuropa.

J. Šiška

- Das Abkommen der Vereinten Nationen über die Rechte von Menschen mit Beeinträchtigung, Artikel 19, sagt, dass es ein Menschenrecht ist, Menschen mit Beeinträchtigung dabei zu unterstützen, in der Gemeinschaft zu leben.
- Einige europäische Länder wie Tschechien, Österreich, Ungarn, Kroatien, Slowenien, Polen und Mazedonien gehörten zu den ersten Ländern, die diesem Abkommen zustimmten.
- Dieser Artikel soll zusammenfassen, was wir über Hindernisse und Möglichkeiten wissen, um Menschen mit Beeinträchtigung dabei zu unterstützen, in der Gesellschaft zu leben wie jeder andere auch.
- Trotz vielen guten Entwicklungen in gesellschaftlichen Diensten, bleibt die Einbindung von Menschen mit Beeinträchtigung gering.
- Einige Beispiele von positiver Veränderung werden vorgestellt.

## Institution, house or something in-between: the current state of deinstitutionalisation in Central and Eastern Europe

J. Šiška

- The United Nations Convention of Rights of Persons with Disability, Article 19, spells out that supporting disabled people to live in the community is an issue of human rights.
- Some European countries such as Czech Republic, Austria, Hungary, Croatia, Slovenia, Poland, and Macedonia were among the first countries to agree with the UN CRPD.
- This paper will summarise what we know about the current barriers and opportunities to support disabled people to live in community as everybody else.
- Despite overall positive developments in community based services, social integration of people with disabilities still remains limited.
- Some examples of positive change will be presented.

## Förderung der Gesundheit und der Gesundheitsfürsorge für Menschen mit intellektueller Beeinträchtigung

L. Taggart

Es wurde gezeigt, dass Menschen mit intellektueller Beeinträchtigung ein höheres Risiko haben, früher zu sterben als Menschen ohne intellektuelle Beeinträchtigung. Menschen mit intellektueller Beeinträchtigung leiden auch öfter an Herzerkrankungen, haben öfter Atemschwierigkeiten, Erkrankungen im Magen oder Darm und andere Erkrankungen.

Die UN-Konvention über die Rechte von Menschen mit Beeinträchtigung sagt, dass jeder das Recht auf die beste Gesundheit hat und dass niemand benachteiligt werden darf. Eine Konvention ist ein Dokument über die Rechte von Menschen mit Beeinträchtigung.

Trotzdem haben viele Menschen mit intellektueller Beeinträchtigung noch nicht dieselbe Gesundheitsfürsorge wie Menschen ohne intellektuelle Beeinträchtigung.

Deshalb sind folgende Punkte sehr wichtig:

Man muss Menschen mit intellektueller Beeinträchtigung unterstützen, ihre Gesundheit beim Arzt kontrollieren zu lassen. Nach dieser Kontrolle kann man dann einen Plan für eine bessere Gesundheit machen.

Menschen mit intellektueller Beeinträchtigung müssen mit ihren Familien, mit Ärzten und Helfern zusammenarbeiten um die Gesundheit von Menschen mit intellektueller Beeinträchtigung zu verbessern.

Menschen mit intellektueller Beeinträchtigung müssen vollen Zugang zu Gesundheitsprogrammen haben.

Wenn Menschen mit intellektueller Beeinträchtigung nicht die Möglichkeit haben, Zugang zu erhalten, dann müssen sich die Gesundheitsprogramme an Menschen mit intellektueller Beeinträchtigung anpassen.

Menschen mit intellektueller Beeinträchtigung, ihre Familien, Ärzte und Betreuer müssen gemeinsam für eine bessere Gesundheit von Menschen mit intellektueller Beeinträchtigung arbeiten.

Gesundheitsprogramme wollen auch, dass Menschen selbst lernen, gesünder zu leben. Sie sollen gesünder essen und Sport betreiben. Menschen mit intellektueller Beeinträchtigung müssen in diese Programme aufgenommen werden. Das kann durch Bildung geschehen, durch leicht zu lesende Informationen, durch Rollenspiele und vieles mehr.

## Health promotion and healthcare for people with intellectual disabilities

L. Taggart

It has been shown that people with intellectual disabilities have a higher risk to die earlier compared to people without intellectual disabilities. They also more often have heart diseases, respiratory problems, health problems with stomach and intestine and many other diseases.

The UN Convention on the Rights of Persons with Disabilities says that everybody has the right on best health and nobody should be discriminated. The Convention is a document about rights of persons with disabilities. But, many persons with intellectual disability do not yet have the same healthcare as people without intellectual disabilities.

Therefore the following is important:

People with intellectual disability must be supported to make health checks at their family doctors. After this check, a plan for a better health can be made.

People with intellectual disabilities, their families, doctors and support staff must work together for a better health for people with intellectual disability.

People with intellectual disability must have full access to health-care programs.

If people with intellectual disability are not able to have access to programs, programs must adapt to people with intellectual disability.

Health programs want that people also learn to live healthier. People should eat healthy, exercise and so on. People with intellectual disabilities must be included in those programs. This can be done by education, easy to read information, role play and much more.

*Thema: Unterstützte Entscheidungsfindung*

### Inklusive Forschung mittels Participatory Action Approach

Cobigo, Virginie

Ziel: Wir haben untersucht, wie personen-zentriertes Planen eine Gemeinschaft für Menschen mit Beeinträchtigungen einladender machen kann. Wir haben uns entschieden, Erwachsene mit Beeinträchtigungen und deren Assistenten einzuladen, um aktive Mitglieder des Forschungsteams zu werden. Wir möchten von der Umsetzung und von den Vor- und Nachteilen berichten.

Methode: Wir haben darauf geachtet, dass bei unseren Treffen jeder die Möglichkeit hatte, sich zu äußern. Wir schrieben alles Gesagte auf. Wir haben gemeinsam beschlossen, wie man über Dinge spricht und das Wichtigste hervorhebt. Dabei haben wir Bilder als Hilfsmittel verwendet. Jeder erzählte von etwas das ihm vertraut ist, sodass wir voneinander lernten. Außerdem sprachen wir darüber, was jeder einzelne tun kann, um anderen zu helfen.

Ergebnisse: Wir reflektierten unsere Vorgehensweise. Einige Dinge funktionierten gut, andere weniger. Es ist möglich, Menschen mit Beeinträchtigungen in die Forschung miteinzubeziehen, sofern sie handlungsbezogen ist.

Schlussfolgerung: Es ist wichtig, Menschen mit Beeinträchtigungen in die Forschung über oder für sie einzubeziehen. Es ist zeitaufwändig und es braucht viele weitere Dinge, wie zum Beispiel mehr Personal zur Assistenz. Schwierig wird es, sobald diese Ressourcen nicht vorhanden sind.

*Topic: Supported Decision Making*

## Inclusive Research using a Participatory Action Approach

Cobigo, Virginie

Aim: We are studying how person-directed planning can make a community more welcoming to persons with disabilities. We decided to ask adults with disabilities and those who support them to be active members of the research team. We want to tell others how we did this and talk about the benefits and problems we saw.

Method: We made sure that everyone got a chance to talk during meetings and we wrote down what everybody said. Together, we decided how to talk about things and what was most important. We used pictures to help us. Each person talked about the things that he/she knew so we learned from each other. We also talked about things that we could do to help others learn.

Results: We looked at how well our way of doing things worked. Some things work better than others. It is possible to include adults with disabilities in research when it is action focused.

Conclusions: It is important to include persons with disabilities in research about or for them. It takes time and staff needs to be given the time to help the people they support participating. This is difficult when there are not enough resources.

## Inklusive Forschung mit Menschen mit Beeinträchtigungen- ein struktureller Literaturüberblick

Frankena, Tessa

Ziel: Immer häufiger arbeiten Menschen mit IB mit Forschern zusammen, um etwas über IB herauszufinden. Diese Vorgehensweise nennt man inklusive Forschung. Allerdings gelingt diese Zusammenarbeit nicht immer so, wie sie sollte. Aus diesem Grund wollten wir herausfinden, wie die Zusammenarbeit zwischen Forschern und Menschen mit IB am besten funktionieren kann.

Methode: Wir versuchten herauszufinden, wie Menschen mit IB und Forscher am besten zusammenarbeiten können. Deshalb lasen wir 21 Artikel von Kollegen, die bereits Erfahrung in dieser Zusammenarbeit haben. Diese Methode nennt sich strukturelle Literaturübersicht.

Ergebnisse: Wir haben drei wichtige Dinge herausgefunden:
Forscher sollten:

1. verschiedene Arten des Zusammenarbeitens mit Menschen mit IB kennen.
2. Pläne über die Zusammenarbeit mit Menschen mit IB machen.
3. Von Kollegen, die bereits Erfahrung in der Zusammenarbeit mit Menschen mit IB haben, lernen.

Schlussfolgerung: Forscher sollten sich der verschiedenen Möglichkeiten der Zusammenarbeit mit Menschen mit IB bewusst sein. Außerdem sollten Forscher beachten, welche Form der Unterstützung die Zusammenarbeit vereinfachen könnte.

## Inclusive research with people with disabilities – a structured literature review

Frankena, Tessa

Aim: More and more, people with intellectual disabilities work together with researchers in research about intellectual disabilities. This is called inclusive research. However, working together does not always work out the way it should. Therefore, we wanted to find out how people with intellectual disabilities and researchers can work together best.

Method: We tried to figure out how people with intellectual disabilities and researchers can work together best, by reading 21 articles written by colleagues who already have experience in working together. This is called a structured literature review.

Results: We found three important points:

Researchers need to:

1. know all the different ways in which they can work together with people with intellectual disabilities.
2. make plans about when and how they want to work together with people with intellectual disabilities.
3. learn from colleagues who have experience in working together with people with intellectual disabilities.

Conclusions: Researchers need to be more aware of all the different possibilities for working together with people with ID. Also, researchers should pay attention to the support people with intellectual disabilities might need, so working together gets easier.

## Eine Hilfe zur Erleichterung von eigenen Entscheidungen mittels Video

Goodwin, Julian

Menschen mit IB wollen Entscheidungen über ihr Leben treffen. Genau wie jeder andere auch, müssen sie Informationen verstehen, um Entscheidungen treffen zu können.
In Großbritannien sind viele Dienstleistungen und Amtsdokumente in „Leichter Sprache“ geschrieben. Aber in einigen Fällen können DVDs und Videos das Verständnis vertiefen.

- Wie erklärt man jemandem mit IB etwas?
- Hilft ihnen das dabei, ihre eigene Entscheidung zu treffen?

Dieser Vortrag basiert auf zwei verschiedenen Projekten. Im ersten Projekt gingen wir zu drei Selbstvertreter-Gruppen. Diese erlaubten uns, die Videokamera mitzunehmen. Wir nahmen ihre Aussagen zum Thema „Leichte Sprache“ auf. Im zweiten Projekt, erstellten wir unsere eigene DVD zum Thema persönliches Budget. Die DVD soll helfen, über die eigenen Unterstützungspläne zu sprechen.

Wir entdeckten verschiedene Arten, das Video zu benutzen. Man kann sich selbst filmen, um sich das Video danach noch einmal anzuschauen. Dabei kann man verstehen, was passiert und schließlich selbstbewusster Entscheidungen treffen. Außerdem kann man Videos benutzen, um Informationen zu vermitteln. Am Ende werden wir darüber sprechen, was unter einer Entscheidung zu verstehen ist, wie Menschen mit anderen zusammen Entscheidungen treffen und wir werden über die feine Linie zwischen Beratung und Überzeugung diskutieren.

## Using video to help people make their own decisions

Goodwin, Julian

People with intellectual disabilities want to make decisions about things in their lives. Just like anyone else, they need to understand information in order to make decisions.

In the UK, lots of services and government papers are written in ‘easy read’. But sometimes videos and DVDs can help people understand better.

- How do people explain things to someone with an intellectual disability?
- Does that help them to make their own decisions?

This talk is based on 2 different projects. In one project, we went to three self-advocacy groups. They let us take a video camera, and we filmed people talking about easy-read information. In another project, we made our own DVD about ‘personal budgets’, to help people speak up about their own support plans.

We found out that video can be used in different ways; people can film themselves, and then watch it back. That may help them to see what’s going on, and to get more confident in making decisions. Video can also be used to give information. We will end by talking about what a decision is, how people make decisions together with others, and the fine line between advising and persuading.

## Selbstvertreter gestalten Unterstützungs-Dienstleistungen

Hopkins, Rob & Minogue, Ger & Hogan, Brian

Ziel: Thema des Vortrages ist eine inklusive Studie über Selbstvertretung in der Republik Irland. Dabei wurde untersucht, wie Selbstvertretung Menschen dazu bringt, sich ihrer eigenen Fähigkeiten bewusst zu werden und somit selbstständig Veränderungen zu erreichen. Das gewonnene Wissen wurde dann eingesetzt, um den Dienstleistungssektor anzuregen und zu verändern. An dieser Studie nahmen Menschen aus drei Dienstleistungsorganisationen und aus einer Gruppe von Selbstvertretern teil.

Methode: Die Forscher bildeten drei Fokusgruppen und sprachen mit vier Fürsprechern von Selbstvertretung, drei Selbstvertretern, drei CEOs und mit dem Vorsitzenden einer unabhängigen Organisation von Selbstvertretern. Sie wollten herausfinden, wie Selbstvertretung organisiert ist, was Selbstvertretung in den Organisationen bewirkt und inwiefern sie ihre Handlungen als wirksam beurteilen würden.

Ergebnisse: Die Untersuchung zeigte, dass Selbstvertreter in Sitzungen mit der Geschäftsleitung und beim Präsentieren auf Konferenzen einbezogen wurden.

Schlussfolgerungen: Es scheint sich bezüglich der Probleme, welche die Selbstvertreter selbst aufgebracht haben, wenig geändert zu haben.

Anwendung des Gelernten: Die Ergebnisse dieser Studie wurden von einer service-orientierten Selbstvertretungsorganisation verwendet, um ihre Aufgabenfelder zu überprüfen. Zum Beispiel um Strategien zu entwickeln, welche die Unabhängigkeit der Organisation gewährleisten und Veränderungen durch Unternehmensberatung bewirken. Des Weiteren wurde diese Gruppe beauftragt, ein bundesweites Selbstvertretungstraining an Hand der neuen Richtlinien der Regierung durchzuführen.

## Self-Advocates Shaping Support Services

Hopkins, Rob & Minogue, Ger & Hogan, Brian

Aim: The presentation demonstrates how an inclusive research study of self-advocacy in the Republic of Ireland led people to develop a critical awareness of how their voices can affect change. They then show how they put this knowledge into action to challenge and modify service delivery. The study involved people in three service organizations and one independent self-advocacy group.

Method: Researchers facilitated three focus groups and interviewed 4 advocate supporters, 3 self-advocates, 3 CEOs and the chair of an independent self-advocacy organization. To explore how self-advocacy was organized, what self-advocates did in each organization and how people felt their actions were effective.

Results: The research revealed self-advocates were involved in meetings with senior management and presenting at conferences.

Conclusions: Little seemed to have changed regarding issues raised by self-advocates.

Application of Learning: Since the research finished its results have been used by one service based self-advocacy organization to critically review its role, developing strategies to support the independence of the group and to effect change through management consultation. The group has been commissioned to deliver a national program of self-advocacy training regarding the government's new independent standards regime.

## Entwicklung eines strategischen Plans in einer kleinen Einrichtung für Menschen mit IB Mittels wertschätzender Befragung

Jackson, Richard

Ziel: 53 Personen haben zusammengearbeitet. Sie haben versucht einen strategischen Plan für ein IB-Service zu entwickeln.

Methode:
Jeder wurde gleich behandelt.
Wir haben in kleinen Gruppen und in 2 großen Gruppen, die wir Workshops nannten, zusammengearbeitet.
Wir haben eine wertschätzende Befragung benutzt, um den Plan zu erstellen.
Wir haben herausgefunden, worin wir gut sind.
Was wollen wir für die Zukunft?
Was können wir tun, damit das eintritt?
Richard zeichnete alles auf und hat uns dann erzählt, was wir gesagt haben.

Ergebnisse:
Wir haben uns für Veränderungen entschieden. Folgend sind einige aufgelistet:
Den Menschen zu helfen, in einer unterstützenden Gemeinschaft so zu leben, wie sie es möchten.
Möglichkeiten für älter werdende Menschen zu planen.
Menschen zu unterstützen, damit sie Computer und IPads benutzen können.
Autos kaufen, damit wir uns mehr in die Gesellschaft eingliedern können.

Schlussfolgerung:
Wir haben gelernt, dass wir alle gleichwertig sind
und alle zusammen sitzen und zusammen sprechen
und darüber nachdenken was wir gut machen
und was wir wollen, können wir zusammen entscheiden, was das Beste für die Zukunft ist.

## Using Appreciative Inquiry to develop a strategic plan in a small service for people with intellectual disabilities

Jackson, Richard

Aim:
53 people worked together to develop a strategic plan for an ID service that will last for three years.

Method:
Everyone was treated the same.
We spent time in small groups and in two large groups called workshops.
We used Appreciative Inquiry to help us make the plan.
We found out what we are good at, what we want for the future and what we can do to make it happen.
Richard recorded everything and told us what we said.

Results:
We decided to make some changes. Below are a few of them:
Helping people to live as they want to live supported in the community.
Plan options for people when they get older.
Support people to use computers and IPADS.
Buy cars to help us get into the community more.

Conclusions:
We learnt that when we are all equal
and all sit down and talk together
and think about what we do well
and what we want, we can decide together, what is best for the future.

## Empowerment Project – Three Stages of Inclusion in the University for Students with Intellectual Disability

Lifshitz, Hefziba

Ziel:
Empowerment beschreibt drei Stufen der Inklusion in der Universität für Menschen mit IB.
Stufe 1: Einmal pro Woche besuchen Menschen mit IB und ohne Down Syndrom die School of Education, Universität Bar-Ilan, Israel. Dort lernen sie über: Psychologie, Selbst-Vertretung, Bibliotheken, und Computer.
Stufe 2: Eine andere Gruppe ist an einem Forschungsseminar beteiligt, indem sie gemeinsam mit anderen Studenten forschen.
Stufe 3: Fünf Studenten mit IB, die über sehr gute Fähigkeiten verfügen, sind in ein Bachelor-Studium integriert. Dort bekommen sie akademische Kredite anerkannt, wenn sie alle Voraussetzungen erfüllen.
Das Ziel dieser Studie war es, den Einfluss dieses Projektes auf die kognitiven Fähigkeiten von Studenten mit IB zu untersuchen.

Methode:
60 Erwachsene mit IB (25-55 Jahre alt), mit und ohne Down Syndrom nahmen teil. Die Hälfte nahm an dem Projekt teil und die andere Hälfte nicht. Die Tests beinhalteten eine Reihe von kognitiven Tests: verbal und non-verbal.

Ergebnisse:
Die Ergebnisse weißen darauf hin, dass die Teilnahme an akademischen Kursen einen Einfluss auf die Leistung der Teilnehmer mit IB in den kognitiven Tests hat.

Schlussfolgerung:
Die Ergebnisse unterstützen die „compensation age theory (Lifshitz – Vahav, 2011)“. Diese Theorie besagt, dass erwachsene mit IB lernen können und mit fortgeschrittenem Alter ihre Fähigkeiten verbessern können.

## Empowerment Project – Three Stages of Inclusion in the University for Students with Intellectual Disability

Lifshitz, Hefziba

Aim:

Empowerment describes three Stages of inclusion at the university for students with ID.

Stage 1: Once a week students with ID with and without Down syndrome attend to the School of Education, Bar- Ilan University, Israel. The courses that they study are: Psychology, Self-Advocacy, Library, and Computers.

Stage 2: Another group is included in a research seminar, conducting research with regular students.

Stage 3: five highly capable students with ID are integrated in two undergraduate courses. They will get academic credits if they fulfill all the requirements.

The goal of the study was to examine the contribution of this project to cognitive ability of students with ID.

Method:

60 adults with ID (age 25-55), with and without DS participated. Half of them participated in the project and half did not. The tests included several cognitive tests: verbal and non-verbal.

Results:

The results indicate that participation in Academic course contributes to the performance of the participants with ID in the cognitive tests.

Conclusions:

The findings support the compensation age theory (Lifshitz – Vahav, 2011). This theory claim that adults with ID can learn and can be modified even at advanced age.

## So geht es mir – Ein personenzentriertes Hilfsmittel zur Beschreibung des Unterstützungsbedarfs

Rajalahti, Aarne

Menschen mit Beeinträchtigungen sollten in Situationen, in denen ihre Unterstützung geplant wird und wo Entscheidungen über ihr Leben getroffen werden, miteinbezogen werden. Wir haben in Finnland ein Hilfsmittel entwickelt, welches es Menschen mit IB erleichtern soll ihren Unterstützungsbedarf selbst beschreiben zu können.

Das Hilfsmittel nennt sich „So geht es mir!“ Es behandelt Themen wie

- Mein jetziges Leben
- Meine Stärken und Schwächen
- So kommuniziere ich
- Diese Dinge mag ich
- Diese Dinge mag ich nicht

Außerdem sind Fragen bezüglich des Alltags, Beziehungen, Arbeit, Freizeit, Gesundheit und Sicherheit enthalten. Mit diesen Fragen wollen wir verstehen

- In welchen Dingen die Leute normalerweise Unterstützung brauchen?
- Wie oft sie Unterstützung benötigen?
- Wie kann man die Leute am besten darin unterstützen, ihr Leben so zu führen, wie sie es sich wünschen?

Während der Entwicklung haben wir das Hilfsmittel oft an verschiedenen Personen mit IB getestet.

Wir haben herausgefunden, dass das Hilfsmittel Personen mit IB hilft, ihren Unterstützungsbedarf zu beschreiben. Außerdem half es, sie in die Planung ihres Unterstützungsbedarfs einzubinden.

Sie können sich das Hilfsmittel „So geht es mir!“ auf Finnisch hier herunterladen: http://bit.ly/1b9T3zI

## This Is How I Do – A person-centered tool of describing support needs

Rajalahti, Aarne

People with disabilities should be involved in situations where their support is being planned and decisions about their lives are made.

We developed a tool which helps people with an intellectual disability to describe their support needs in Finland.

The tool is called ”This Is How I Do!”. It consists of questions, like

- My life now
- My strengths and skills
- This is how I communicate
- These are the things that I like
- These are the things that I don’t like.

The tool also has many questions about everyday life, relationships, work, leisure time, health and safety. With these questions we try to see,

- In which things people usually need some support?
- How often they usually need support?
- What is the best way to support people to live the kind of life that they choose?

When developing this tool we did it many times with different people with intellectual disabilities.

We found out that the tool works as it helps people to describe their support needs and to be involved in the support planning.

You can download the ”This Is How I Do!”-tool in Finnish here: http://bit.ly/1b9T3zI

## Nichts über uns ohne uns – Gilt das auch für Menschen mit schweren Beeinträchtigungen?

Schmid, Bernhard

Menschen mit schweren Beeinträchtigungen wollen ein selbstbestimmtes Leben führen und dabei sein, so wie andere auch. Doch das ist ganz und gar nicht einfach!

Viele können sich nur schwer verständlich machen. Weil sie selbst kaum sprechen können und nicht verstehen, was andere Leute sagen oder aufschreiben. Was sie nicht unmittelbar sehen, hören oder fühlen, können sie sich nicht oder nur schwer vorstellen. Und sie wissen nicht, warum etwas so oder anders geschieht oder gemacht wird. Einige beeinträchtigte Menschen verhalten sich auch sehr ungewöhnlich: Sie antworten nicht oder wenden sich ab, auch wenn man freundlich mit ihnen reden will. Andere geben laute Geräusche von sich, laufen davon, werfen sich auf den Boden oder greifen andere Menschen gegen deren Willen an.

Dabei bleibt oft unbemerkt, dass Menschen mit schweren Beeinträchtigungen sehr wohl auch eigene Fähigkeiten und Ausdrucksweisen besitzen. Diese müssen nur richtig verstanden und anerkannt werden!
Was kann der Einzelne, was kann die Gesellschaft tun, damit ein Mensch mit schweren Beeinträchtigungen in seiner Würde und mit all seinen Fähigkeiten wahrgenommen und erstgenommen wird? Welche Unterstützung braucht die Person, damit sie ihren Willen und ihre Absichten mitteilen und umsetzen kann?

Bernhard Schmid, Vater eines jungen Mannes mit Down-Syndrom, zeigt anhand einiger Beispiele aus der Praxis, wie es gelingen kann, Menschen mit schweren Beeinträchtigungen in der Gemeinschaft mit einzuschließen und ihnen zu helfen, ein möglichst selbstbestimmtes Leben zu führen.

## Nothing about us without us– Is this also true for people with severe impairments?

Schmid, Bernhard

People with severe disabilities want to live a self-determined and inclusive life as others, too. But achieving this is not easy at all!

Many cannot express themselves to others, because they hardly can speak and they do not understand, what other people say or write to them. They cannot imagine things beyond direct watching, listening or touching.  And they do not know why things happen or are done in this or that way. Some people with disabilities are also behaving rather unusual. They do not answer or move away when someone wants to talk friendly to them. Others utter loud noises, run away, pull themselves to the ground or touch people against their will.

Often it remains unrecognized, that people with severe disabilities have very well own capacities and ways of expression. They only need to be understood and accepted properly!

What can be done by each single person and by our society as a whole, so that a person with severe disabilities is realized and taken seriously in his or her dignity with all of his or her capacities? Which support the person requires, so that he or she can tell and execute his or her will and preferences?

Bernhard Schmid, a father of a young man with Down syndrome, illustrates based on examples from practice, how people with severe disabilities can be included in society and be supported for living their life as self-determined as possible.

## Das Mitspracheteam der Lebenshilfe Wien berichtet über seine Arbeit

Hochmeister, Josef

In unserer Rede werden wir über die Gruppe MiT sprechen. Gruppe MiT ist die Abkürzung für Mitspracheteam.

Die Gruppe MiT gibt es seit 3. September 2012.In der Gruppe arbeiten 6 Personen und 2 Unterstützerinnen. Wir haben auch eine Praktikantin.
In der Gruppe MiT machen wir Selbstvertretungsarbeit. Wir sind unsere eigenen Chefs und wollen nicht immer unter Kontrolle sein. Als eigene Chefs planen wir in unserem Büro unseren Alltag selber. Wir entscheiden was wir an einem Tag machen wollen.

In der Gruppe arbeiten wir mit dem Kopf. Wir machen uns Gedanken über die Dinge, besprechen unsere Gedanken in der Gruppe und ordnen unsere Gedanken. Später tauschen wir unsere Gedanken auch mit anderen aus. Zum Beispiel mit anderen Selbstvertretern.

In unserer Arbeit in der Gruppe haben wir viele Dinge über uns selber herausgefunden. Zum Beispiel haben wir in der Gruppe mehr Mut Dinge selber auszuprobieren.

Weil die Gruppe MiT etwas Besonderes ist, wollen wir in unserem Vortrag unser Wissen weitergeben. Wir wollen erzählen wie es bei uns in der Arbeit abläuft. Wir wollen das Lehrer und Lehrerinnen an Schulen und Universitäten das Wissen über die Gruppe MiT weitergeben. Wenn man unser Wissen weitergibt, dann können andere Menschen das für sich auch aufgreifen.

*Topic: Inclusion in the Workplace*

## The “User Participation Team”

Hochmeister, Josef

In our presentation we will speak about the „Gruppe MiT“. “Gruppe MiT” is German and means “Group MiT”. It is a shortcut for “Mitspracheteam”. That means “User Participation Team”.

The Group started on September, 3rd 2012. In the group are working six persons and two supporters. We also have a trainee.

In the group we are doing self-advocacy work. We are our own bosses and don’t want to be under control all the time. As our own bosses we plan our everyday live on our own. Every day we decide what we want to do.

In the group we work with our heads. We are thinking about topics, discuss them in the group and sort our thoughts. Later on we also speak about our thoughts with other self-advocates, for example in our self-advocacy group.

In our work we discover a lot of things about ourselves. For example: In our group we have more courage to try out new things on our own.

Because our group is something special we want to give our knowledge to other people. We want to speak about the way we work. We want to give our knowledge to teachers on schools and universities. When we give our knowledge to other people they can pick up something for themselves.

## Wie ein Job Menschen mit IB helfen könnte, sich besser in die Gesellschaft einzufügen

Humber, Lee

Ich habe herausgefunden, wie viele Menschen mit IB in Großbritannien einen Job haben. Außerdem habe ich versucht herauszufinden, ob der Umstand einen Job zu haben, Menschen mit IB geholfen hat, sich besser inkludiert zu fühlen. Es zeigte sich, dass einige, die einen Job hatten, trotzdem nicht richtig in das Arbeitsumfeld einbezogen wurden.

Ich fragte mehr als 40 Personen mit IB, wie es sich anfühlt, einen Job zu suchen. Die Personen, die bereits einen Job hatten, fragte ich stattdessen, ob sie sich bei der Arbeit inkludiert fühlen. Viele von ihnen antworteten mit Nein.

Mit Hilfe der Interviews gelang es mir einen genaueren Blick auf etwas, das sich Stigma nennt, zu bekommen. Wenn Menschen etwas Schlechtes über Personen mit IB denken – oder auch über jemand anderen -, ist das ein Stigma. Meine Forschung beschäftigte sich mit der Frage, ob man verhindern kann, dass Menschen etwas Schlechtes über Menschen mit IB denken, indem man den Grund für ein Stigma herausfinden würde.

Wenn ich bei dem Kongress meine Rede halte, werde ich einige Vorschläge machen, wie man den Arbeitsplatz für Menschen mit IB inklusiver gestalten kann.

## How getting a job might help people with intellectual disabilities be more included in society

Humber, Lee

I did some research that looked at how many people with intellectual disabilities in the UK had jobs. I also looked at whether having a job helped people feel included and I discovered that even though some people with intellectual disabilities in the UK did find work, they still were not included properly by the places where they worked.

In my research, I interviewed over 40 people with intellectual disabilities to ask them what it felt like looking for a job. Some people I spoke to were in a job and so I asked them if they thought they were being included properly by their places of work. Many of them said no.

Thanks to all of these interviews I was able to look at something called stigma. Stigma is when people think bad things about people with intellectual disabilities – and some other people like those with mental health problems. My research asked whether we can stop people thinking bad things about people with intellectual disabilities by finding out the reasons for stigma.

When I speak at the conference I will suggest some ways of improving how well people with intellectual disabilities are included in society and in workplaces.

## Keine Tageswerkstätten mehr? Über Berufsausbildung, Arbeit in Betrieben und Soziale Arbeit

Krammer, Alois

Alpha Nova ist eine gemeinnützige Organisation in der Steiermark/Österreich.
Mehr Informationen gibt es unter www.alphanova.at.

Wir wollen, dass auch Menschen mit schwereren Behinderungen bei der Arbeit mehr Auswahl haben.
Jetzt gibt es oft nur die Tageswerkstätte.

Deshalb haben wir zwei Angebote entwickelt:
a) Intensive Begleitung bei der Lehre
Menschen mit schwereren Behinderungen machen eine Integrative Berufsausbildung.
Sie machen die Ausbildung in Firmen.
Sie besuchen auch die Berufsschule.
Wir helfen ihnen, eine Lehrstelle zu finden.
Wir unterstützen sie direkt am Lehrplatz.
Wir helfen ihnen, dass sie die Berufsschule und die Abschlussprüfung schaffen.
Die Lehrlinge bekommen ein Gehalt.
Viele haben später einen Job im Lehrbetrieb.

b) Beschäftigung in Betrieben (anstatt in einer Werkstätte)
Viele Menschen mit Behinderung wollen keine Lehre machen oder finden keinen Arbeitsplatz. Und sie wollen nicht in eine Tageswerkstätte.
Bei unseren „Integrierten Arbeitsgruppen“ haben sie eine Arbeit in Firmen.
Eine Assistentin ist immer dabei.
Sie brauchen keine Werkstätte.

Wir wollen die einzelnen KundInnen gut fördern und unterstützen.
Gleichzeitig sind wir dafür da, dass der Arbeitsplatz gut ist.
Und dass unsere KundInnen gut mit den anderen MitarbeiterInnen der Firma auskommen.
Deshalb haben unsere MitarbeiterInnen nicht nur gute pädagogische Kenntnisse.
Genauso wichtig sind für sie Methoden der Sozialen Arbeit.

## No sheltered workshops anymore? On supported apprenticeship, inclusive employment and social work.

Krammer, Alois

Alpha Nova is a non-profit organisation in Styria/Austria (see www.alphanova.at).

We want that more people with rather comprehensive disabilities have more choices concerning their employment.
At the moment very often only sheltered workshops are available.

Therefore we developed two assistances:

a) Supported apprenticeship

People with major disabilities successfully complete an apprenticeship.
The practical training takes place in a company.
The theoretical training takes place in a vocational training college.
The apprentices get an ordinary salary.
We assist them in their job.
We help them to learn the theoretical matters.
At the end they have an accredited certification about their vocational competence.
Many of them get jobs in the companies immediately afterwards.

b) Inclusive employment in companies

This is a service for people with intellectual disabilities as an alternative to sheltered workshops (the same group).
People with major disabilities do work and get assistance in companies.
They do not need sheltered workshops anymore.
An assistant is always present.

We support every person individually.
At the same time we try to guarantee a good workplace.
And we support the communication with the other employees.
Our assistance is focused both on the individual and the (social) environment.
Therefore our employees do not only have pedagogical knowledge.
As important as that are methods of social work.

### Der Werkstattrat aus Sicht von Menschen mit Lernschwierigkeiten

Saugspieler, Robert

In unserer Rede werden wir über Werkstatträte sprechen. Werkstatträte sind Menschen mit Lernschwierigkeiten, die sich in den Werkstätten für ihre Kollegen und Kolleginnen einsetzten.

Wir erzählen Ihnen warum es wichtig ist Werkstatträte zu haben. Dazu erklären wir wie Werkstatträte als Personen sein sollten und ihre Rolle in der Werkstatt.
Wenn es einen Werkstattrat gib werden sich einige Sachen für Klienten und Klientinnen verändern. Was wir und dazu gedacht haben werden wir erzählen.
Wir werden auch erklären was die Aufgaben des Werkstattrats sind und wie die Wahlen in der Werkstatt ablaufen sollen.

## The sheltered workshop counsellor

Saugspieler, Robert

In our presentation we will talk about sheltered workshop counsellors. Sheltered workshop counsellors are people with learning disabilities, which are peer advocates for their colleges in sheltered workshops.

We will tell you why it is important to have a sheltered workshop counsellor. Thereto we will explain how counsellors have to be and which role they play in workshops.

If sheltered workshops have workshop counsellors some things will change for people with learning disabilities who work there.

In our presentation we will talk about our thoughts about sheltered workshop counsellors.

We (also) will speak about the tasks the workshop counsellor has to perform and how the voting of the workshop counsellor should run too.

## Wenn KlientInnen zu KollegInnen werden

Stubenrauch, Gudrun

ZIEL:
Menschen mit Behinderungen konnten bisher keine Berufsausbildung im Sozialbereich absolvieren.

Viele haben aber gute Voraussetzungen dafür und auch Interesse an einem Sozialberuf.

METHODE:
Im Rahmen eines EU Projektes (IBB) wurde eine integrative Berufsausbildung zur FachsozialhelferIn entwickelt.
An mehreren Schulstandorten (Schulen für Sozialbetreuungsberufe) in Österreich können Menschen mit Lernschwierigkeiten erstmals eine Berufsausbildung im Sozialbereich absolvieren.
Die Ausbildung dauert 2 Jahre.

ERGEBNISSE:
Die FachsozialhelferInnen arbeiten im Betreuerteam.
Sie übernehmen Hilfstätigkeiten in der Begleitung von Menschen mit Behinderung.
Ein spezielles Diversity Training und Mentoring Programm unterstützen beim Berufseinstieg.

Mit dem Projekt wurde für Menschen mit Lernschwierigkeiten eine Berufsausbildung im Sozialbereich geschaffen. Daraus ergeben sich neue Arbeitsplätze im Sozialbereich.

## People with learning difficulties become colleagues

Stubenrauch, Gudrun

AIMS:

Until now, persons with learning difficulties haven’t had access to vocational training and jobs in the social sector.

But many of them have good requirements and big interest in a social profession.

METHOD:

From 2003 to 2006 in the European Project (named IBB) an inclusive training model was developed.

People with disabilities become advisers for persons with disabilities themselves.

In Styria the vocational training started at 2009, schools in Vorarlberg, Salzburg und Carinthia are interested.

RESULTS:

With the inclusive training model, people with disabilities for the first time ever were able to participate in a vocational training in the social sector.

The participants become an assistant in care work.

The care assistant is part of the care-team.

They assume basic tasks in the care institutions.

A special diversity training and mentoring program support the process of integration in employment.

## Im Spannungsfeld zwischen Selbstbestimmung und gesellschaftlichen Erwartungen, Eine kritische Herangehensweise

Ronge, Angelika

Selbstbestimmung am Arbeitsplatz ist eine große Chance für Menschen mit Lernschwierigkeiten.
Das, was Menschen mit Lernschwierigkeiten selbst bestimmen möchten und das was andere Menschen als Selbstbestimmung sehen, passt nicht immer zusammen.
Die anderen Menschen am Arbeitsplatz erwarten Anpassung und das Einhalten von Pflichten.
Werden diese Pflichten nicht erfüllt ist die Inklusion von Menschen mit Lernschwierigkeiten am Arbeitsplatz gefährdet.
Wenn man nach der Schule einen Arbeitsplatz haben möchte, muss man sich an gewisse Spielregel halten.
Trotzdem hat jeder Mensch ein Recht auf ein selbstbestimmtes Leben, im Privatleben wie auch am Arbeitsplatz.
Nicht jeder ist in der Lage alle Möglichkeiten der Selbstbestimmung wahrzunehmen.
Inklusion und Selbstbestimmung soll Menschen mit Lernschwierigkeiten unterstützen, gleichberechtigt an allen Lebensbereichen teilnehmen zu können.
Menschen mit Lernschwierigkeiten benötigen Unterstützung um selbst bestimmen zu können und am Arbeitsleben gleichberechtigt teilnehmen zu können.
Diese Unterstützung bekommen sie von der Familie, Assistentinnen im Wohnen und Arbeiten, Job Coaches und Arbeitgeberinnen.
Die Art der Unterstützung ist sehr unterschiedlich, daher wird das Schlagwort Selbstbestimmung von Menschen mit Lernschwierigkeiten auch verschieden wahrgenommen.
Menschen mit Lernschwierigkeiten haben nicht immer ein klares Ziel und die Fähigkeit durch Reden und Tun ihr Ziel zu verfolgen.
Wegen der unterschiedlichen Ansichten von Assistentinnen über das, was Selbstbestimmung ist, kennen sich Menschen mit Behinderung nicht mehr aus. Sie fühlen sich zerrissen und sind überfordert.
Selbst bestimmen zu können, ist nicht nur das Durchsetzen der eigenen Wünsche.
Menschen mit Lernschwierigkeiten müssen als selbstbestimmte Menschen am Arbeitsplatz auch die bestehenden Spielregeln und Rollen beachten. Dieses Problem wird im Vortrag durch Beispiele erklärt.

## People with cognitive disabilities in tension between self-determination, equal participation and social expectations. A critical approach

Ronge, Angelika

Self-determination in the workplace is a great opportunity for people with special needs.
However self-determination in the workplace also requires that the needs of the working place are met.
If these duties are not fulfilled, inclusion for people with special needs in the workplace may be at risk.
If you want to move from school to working life you have to adapt to society’s rules.
How people with special needs see self-determination and participation is often not how society does.  Society expects adaption.
Nevertheless all people have the right to a self-determined life both in private life and in the workplace.
Not everyone is able to conceive the opportunities of self-determination.
Inclusion and self-determination should support people with special needs in having access to all areas of life.
People with special needs need to be supported in participation and self-determination.
They receive this support from their family, educational professionals in vocational training and living facilities, job coaches and employers.
The kind of support is diverging and that is why the term “self-determination” is also experienced differently.
People with special needs do not always have their direction of life clearly in mind.
They often do not have the skills and knowledge to pursue their goals.
Because the term „self-determination“ is experienced differently, people with special needs often do not know what it means and feel confused.
Self-determination is not to only think of yourself and your wishes.
People with special needs as self-determined people in working place must stick to social rules and roles. This problem will be explained in the course of the talk.

## Eine Reise bis zum Ende des Lebens

Allan, Meredith

Während der IASSIDD Konferenz in Halifax teilte mir meine Schwester mit, dass sie unseren Vater ins Krankenhaus einweisen musste. Als unser Vater nur acht Wochen darauf starb, war das schwer zu realisieren. Menschen schauen auf eine Familie in der eine Beeinträchtigung vorkommt und sehen nur ein einseitiges Geben. In unserer Familie ist das Geben beidseitig. Diese Arbeit beschreibt die Reise, die ich in diesen acht Wochen mit meiner Familie durchlebt habe.

Mein Vater stellte meine Kommunikationshilfen her. Das war sehr schwierig für ihn, da seine Handschrift nicht die beste war. Deswegen bat er oft andere um Hilfe oder benutzte Buchstaben aus der Zeitung. Das war vor den Zeiten des Computers. Auch Schreibmaschinen gab es nicht in jedem Haushalt. Mein Vater war ein Landwirt, Gärtner und Erfinder. Er konnte alles reparieren. Er war meine erste Ansprechperson, wenn ein Spielzeug kaputt gegangen war. „Papa, reparier‘ das!“ war mein erster Satz.

In dieser Arbeit geht es hauptsächlich um die Reise durch die letzten paar Wochen im Leben meines Vaters. Außerdem geht es um Familie, Geschwister und über die Wichtigkeit lebenslanger Kommunikation.

*Topic: Community Based Living*

## A Journey through the end of life

Allan, Meredith

During the IASSID conference in Halifax, my sister emailed me that she had admitted my father to hospital. Little did we realize eight weeks later my father would be dead. People look at a family who has a family member with a disability and only see the one way flow of giving. We are very much family where the giving is both ways. This paper is the journey I took with my family through these eight weeks

My father made my Communication boards and books, it was difficult for him as he did not have the greatest hand writing in the world, he always roped somebody else in to do the writing or used letters from Newspapers. This was in the days before computers. Typewriters were not a fixture in households. Dad was a farmer, horticultural therapist and an inventor. My Dad could fix anything. Dad was the first to receive my broken toys. “Daddy, fix it!” was my first phrase.

This paper is mainly about the journey through the last few weeks of my father’s life. It is also about family, sibling relationships and the lifelong importance of communication.

### Werkstätte Bischofshofen – Eine Gruppe auf neuen Wegen

Brandner, Brigitte

Wir erzählen von einem guten Bespiel für mehr Teilhabe bei der Arbeit. Wir haben es ausprobiert und es läuft sehr gut.

Wir kommen von der Lebenshilfe Salzburg. In unserer Werkstätte in Bischofshofen gibt es sehr selbständige Menschen mit Lernschwierigkeiten.
PEERS haben sie gefragt, wie sie in Zukunft arbeiten wollen. PEER bedeutet gleichgestellt. Peer-Befrager und Peer-Befragerinnen sind Menschen mit Lernschwierigkeiten, die eine Ausbildung gemacht haben.

Das ist dabei herausgekommen:

- Alle Befragten wollten eine Arbeit außerhalb der Lebenshilfe.
- Sie wollten aber auch die Werkstätte nicht ganz verlassen.

Die Unterstützerinnen und Unterstützer suchten nach passenden Arbeitsmöglichkeiten in den Firmen in der Umgebung.

Die neue Gruppe nennt sich Selbstständige Gruppe.

Jetzt arbeiten alle aus der selbständigen Gruppe ein paar Tage in der Woche in einer Firma. An den anderen Tagen arbeiten sie in der Werkstätte. In der Werkstätte teilen sie sich die Arbeit selbst ein. Sie regeln auch die meisten anderen Dinge selbst.

Die Unterstützerinnen und Unterstützer haben dadurch viel mehr Zeit. Sie können jetzt einzelne Personen am Arbeitsplatz in der Firma begleiten. Und sie können mit jeder und jedem üben, was gebraucht wird. Die Menschen mit Lernschwierigkeiten sind jetzt zufriedener.

Im Vortrag sprechen wir über unsere Arbeitsweise. Wir zeigen auch ein kurzes Video über unseren Arbeitsalltag

## On a new path in work support

Brandner, Brigitte

We take about a good practice of inclusion at work. We tried it out and it works very well.

We are from the Lebenshilfe Salzburg. In our sheltered workshop in Bischofshofen, some clients were under challenged. Therefore they tried to strike a new path in their services. At first peer-interviewer asked the people with learning-disabilities how they want to work in the future. These were the results:

- All respondents wanted an occupation outside of the Lebenshilfe
- But they still wanted to use the services of the sheltered workshop.

The supporters searched for job-opportunities in companies in the environment.

The new group is called „Independent Group". The people in the group now work some days a week at an inclusive workplace. On the other days they still work at the sheltered workshop. They organize their activities and most of the other affairs of their life by themselves.

The supporters have a lot more time now. They use it to support the people with disabilities at the inclusive workplaces. And they have more time for individual trainings.

And the people with disabilities are more contented.

In our speech we tell you more about our Independent Group. We will also show you a short film about our workaday life.

## Ich werde älter – Mein Beitrag für die Gesellschaft

Bruckmüller, Maria

Menschen mit intellektueller und mehrfacher Beeinträchtigung werden älter. Die Lebensbedingungen ändern sich. Wir selbst nehmen täglich darauf Rücksicht. Die Veränderungen betreffen besonders Bewegung und Bildung, Ernährung und Pflege.

Im Alter treten häufig Krankheiten auf. Richtige Behandlung stärkt das Wohlbefinden. Ambulante und stationäre Behandlungen müssen gut aufeinander abgestimmt werden. Neue Erfahrungen werden gesammelt und weitergegeben. Jeder Arzt und jedes Spital kann sie übernehmen.

In Österreich ist eine Gesellschaft von Ärzten und Pflegepersonal entstanden. Sie heißt VUP – das bedeutet “very unequal people” – “sehr ungleiche Menschen”. Dieser neue Verein sorgt für die Verbesserung der ärztlichen Versorgung und Ausbildung. Alle Kenntnisse über intellektuell beeinträchtigte kranke Personen sollen überlegt und weitergegeben werden. Öffentliche Studien können dabei helfen. Alle Menschen lernen voneinander.

## I´m getting older – my contribution to society

Bruckmüller, Maria

People, intellectually and in different forms handicapped, are growing older. Life-conditions are changing. Changes befall mobility and education, nourishment and care.

Old age multiplies illnesses. The right care strengthens well-being. Ambulant and stationary treatment must be carefully balanced. New experiences are collected and transmitted. Every doctor and any hospital can take over.

In Austria, a society of doctors and personal in the care-area came into life. It’s called VUP, which means “very unequal people”. This association takes care of the embitterment of medical care and training. All the knowledge concerning intellectually handicapped sick persons should be well considered and transmitted. Publicized studies can be helpful. We all learn from each other.

## Gesundheit im Alter von Menschen mit Lernschwierigkeiten

Ellbogen, Harald

Auch Menschen mit Lernschwierigkeiten werden immer älter.

Es wichtig, dass das medizinische Personal gut mit Menschen mit Lernschwierigkeiten umgehen kann.

Das Personal soll gut geschult sein.

Jede und jeder muss die Wahl haben zwischen Schulmedizin oder Alternativmedizin.

Jede und jeder muss sich seine Ärztin oder seinen Arzt selbst aussuchen können.

Wir brauchen alle Informationen in leichter Sprache.

## Health in the age of people with learning disabilities

Ellbogen, Harald

People with Intellectual and Developmental Disability are growing older.

It is important, that medical staff have a good way with people with Intellectual and developmental disability.

The staff is to be well grounded.

Everyone must have the opinion between the academic medicine and the alternative medicine.

Everyone must have the possibility to choose the doctor themselves.

We need all information in easy language.

## Erforschung von Ideen und Theorien aus der Forschungsgemeinschaft: ein dreiteiliges Symposium

Grove, Nicola

Bei der Erforschung von Beeinträchtigungen, gibt es aktuell viele gute Forscher, die selbst IB haben. In der Regel werden diese in Entscheidungen über das Thema der Forschung und die Art und Weise, wie Informationen erhoben und präsentiert werden, miteinbezogen. Allerdings haben sie nicht die Möglichkeit, von Theorien und Ideen zu ihrer Forschung zu berichten. Das bedeutet, dass sie aus wichtigen Diskussionen und Debatten ausgeschlossen werden. In dieser Sitzung werden wir gemeinsam daran arbeiten, vier Ideen von Autoren einfacher zu verstehen, die helfen u erklären warum Menschen mit Beeinträchtigungen keine Macht in der Gesellschaft haben. Die Autoren sind Michel Foucault, Gilles Deleuze, Felix Guttari und Gayatri Spivak. Wir werden Bilder, Schauspiel, Skulpturen, Kunst und Geschichten verwenden, um zu verstehen, wie Macht im Alltag wirkt. Wir sind der Meinung, dass das den Glauben, Menschen mit IB wären nicht in der Lage Theorien zu verstehen, herausfordern wird. Außerdem werden wir von integrativen Forschungsteams berichten. Am Ende des Symposiums werden wir Arbeitsmodelle einiger Theorien erarbeitet haben.

## Exploring ideas and theories in the research community: a three session symposium

Grove, Nicola

In disability research, there are now many good researchers who have intellectual disabilities. Usually they get involved in deciding what to investigate, and how to collect and present information. But they may not get the opportunity to talk about the theories and ideas that are connected with their research. This means that they are left out of some important debates and discussions. In this session, we will be working together to find ways of making it easier for people to understand the ideas of 4 writers who have helped to explain why people with disabilities don’t have power in society. The writers are Michel Foucault, Gilles Deleuze, Felix Guttari, and Gayatri Spivak. We will be using pictures, drama, sculpture, craft and storytelling to help us all understand better how power works in our lives. We believe this will challenge the belief that people with intellectual disabilities can’t understand theory, and will read to more inclusive research teams. By the end of the symposium we will have results in the form of working models of some theories.

## Menschen mit einer Lernbehinderung können gute Eltern sein

Illkow, Johanna

Menschen mit einer Lernbehinderung können gute Eltern sein.
Eltern sollten nicht von ihren Kindern getrennt werden.
Manchmal können Eltern aber nicht alleine für ihre Kinder sorgen.
Die UNO-Konvention für Menschen mit Behinderungen besagt, dass es Unterstützung für Eltern mit IB geben muss.
Menschen mit IB können ihre Kinder aufziehen, wenn sie die richtige Unterstützung und Hilfe bekommen.

Es ist wichtig, dass Betreuer lernen, wie sie die richtige Unterstützung im Familienalltag geben können.

Die Begleiter und Begleiterinnen lernen zum Beispiel:

- Wie erklärt man den Eltern gut, was ein kleines Kind wann braucht?
- Wie kann Eltern die Erziehung leichter gemacht werden?
- Wann muss den Eltern Arbeit abgenommen werden?
- Wohin können sich Eltern bei Fragen noch wenden?
- Wie können andere Menschen verstehen, dass Eltern mit einer Lernbehinderung gute Eltern sind?

Wir haben in einem Buch beschrieben,

- wie Begleiter und Begleiterinnen gut ausgebildet werden können,
- welche Möglichkeiten es in anderen Ländern
  für Eltern mit Lernbehinderung gibt,
- wie ein Computer-Kurs für die Arbeit von Begleitern und Begleiterinnen abläuft.

In einigen Ländern wurden das Buch und der Kurs ausprobiert.
Viele Menschen haben das gut gefunden.

### Parents with Intellectual Disabilities-European Family Set

Illkow, Johanna

Parents with learning disabilities can be good parents.
Parents should not be separated from their children.
Sometimes parents with learning disabilities need support to care for their children.
The UN Convention on the Rights of Persons with Disabilities says that there must be support for parents with learning disabilities.
People with learning difficulties can raise their children, if they are given the right support and help.

It is important that care workers learn how to give the right support in every-day family life.

For example care workers learn:

- How to teach parents, all special needs of babies or children.
- How to support parents in raising their children.
- When parents need a break.
- Where parents can ask for good help (family centres, women's groups...).
- That other people have to understand that parents with learning disabilities can be good parents.

We wrote a book about

- Education for assistance of parents with learning disabilities.
- Good support for parents with learning disabilities in other countries.
- We prepared a computer course for assistants to learn important things about supporting parents and children.

The book and the course were tested in several countries and many people liked it.

## Selbstbestimmung im Gesundheitsbereich. Selbstbestimmung im Pflegebereich.

Kaufmann, Eringard

Was wurde bisher laut Gesetz in Österreich gemacht?

Welche Fragen haben Menschen mit Behinderung zu den Gesetzen im Gesundheitsbereich.

Welche Fragen haben Menschen mit Behinderung zu den Gesetzen im Pflegebereich.

Welche Fragen haben Menschen mit Behinderung allgemein zum Thema Gesundheit und Pflege.

Ist es besser zu fragen, wie gesund ein Mensch ist oder ist es besser zu fragen, wie krank ein Mensch ist?

Was bedeutet das?

Was ist der Unterschied?

## The Right of Selfdetermination in Public Health and Care

Kaufmann, Eringard

We look at how the law changed in Austria.

Which questions do persons with disabilities have on the law regarding health?

Which questions do persons with disabilities have on laws regarding care?

Which questions do persons with disabilities generally have regarding health and care?

Is it better to ask how healthy a person is or is it better to ask how unhealthy a person is?

What does this mean?

What is the difference?

## Die Opportunity League (Liga der Möglichkeiten): Ein radikal integrativer Ansatz zur Erholung und Sport

Miller, Martin

Unser Projekt heißt die Opportunity League (OL). Wir haben die Regeln von Teamsportarten wie Basketball und Fußball so angepasst, dass jeder sie spielen kann. Alle Altersgruppen haben teilgenommen. Wir haben uns neue Teamspiele ausgedacht, damit jeder ungeachtet der Schwere seiner Beeinträchtigung, in der gleichen Mannschaft spielen kann. Die Mannschaften traten gegeneinander an. Nach einer Niederlage, lernten die Spieler wie man mit Fehlschlägen umgehen kann und wie sie das nächste Mal besser spielen können. Die benötigten Spielflächen wurden von der Stadt gespendet und inklusiven Spielen gerecht gemacht. Eine Stadt in der Nähe von New York spendete der OL eine Spielfläche. Mehrere Städte werden in nächster Zeit dasselbe tun. Es zeigte sich bei Probespielen, dass körperlich gesunde Spieler Mannschaftskollegen mit jeder Art von Beeinträchtigung akzeptieren, solange sie sich anstrengen. OL verbessert außerdem die Gesundheit und die persönliche und soziale Entwicklung.

Wir haben eine Methode die Bereitschaft von Städten die OL zu unterstützen, zu messen. Wir entwickeln Messmethoden um die Akzeptanz von körperlich gesunden Spielern gegenüber ihren Teamkollegen mit Beeinträchtigungen erfassen zu können. Ebenso entwickeln wir Messmethoden für den umgekehrten Fall. Außerdem möchten wir messen, inwiefern die OL die generelle Einstellung gegenüber Personen mit intellektuellen und/oder entwicklungsbedingten Beeinträchtigungen verbessern kann.

## The OPPORTUNITY LEAGUE: A radically inclusive approach to recreation and sport

Miller, Martin

Our project is called the Opportunity League (OL). Rules of team games like netball or soccer are adjusted so that anybody can play. All age groups take part. New team games are invented so that people of all ability levels can play on the same team. The teams really compete. When a team loses, players learn how to handle failure, and when possible, to play better next time. Fields for playing are donated by the town, and are made safe for inclusive games. A town in the New York area has given a field to the OL. More towns will soon do the same. Trial games show that able-bodied players can accept teammates who have all kinds of disabilities, as long as all the players try hard. The OL is also good for improved health, and for personal and social development.

We have a way of measuring how ready a community is to support the OL. We are working on ways to measure how much able-bodied players accept their teammates who have disabilities, and also the other way around. We will also want to measure how the OL can improve the attitudes of people in general towards people with intellectual and/or developmental disabilities.

## Bundes-Behinderengleichstellungsgesetz

Meierschitz, Christina

Seit 2006 gibt es das Bundes-Behindertengleichstellungsgesetz

Darin steht, dass es keine Diskriminierung von Menschen mit Behinderungen geben darf.

Menschen mit Behinderungen müssen sich wehren können.

Im Gesetz werden die Begriffe „Behinderung“, Diskriminierung“ und „Barrierefreiheit“ erklärt.

Es wird auch erklärt für wen das Gesetz gilt.

Es gibt zum Beispiel das Schlichtungsverfahren.

Das Schlichtungsverfahren muss gemacht werden.

Das Schlichtungsverfahren ist beim Bundessozialamt.

Es hilft Menschen mit Behinderungen,  damit sie nicht benachteiligt werden.

Es hilft Menschen mit Behinderungen, Recht zu bekommen.

Wenn diese Benachteiligung viele Menschen betrifft, kann die ÖAR - Dachverband der Behindertenverbände Österreichs mit einer Klage bei Gericht helfen.

Das Gesetz muss noch verbessert werden.

Es gibt ein Recht darauf, dass es da keine Hindernisse gibt.
Sie bekommen dann eine Antwort von uns.

## Federal Disability Equality Act

Meierschitz, Christina

Since 2006 there is the Federal Disability Equality Act in Austria.

It is a law that says that no one may discriminate persons with disabilities.

The law explains the expressions “disability”, “discrimination” and “accessibility”.

It also explains for whom the law is important.

There is for example the conciliation process.

The conciliation process is obligatory.

The conciliation process is made by the Federal Social Office.

It helps persons with disabilities so that they are not discriminated against.

**Inklusiv Wohnen Wien**

Neira Zuasty, Helga

Das heißt:

*Menschen mit Behinderung und Menschen ohne Behinderung wohnen gemeinsam in einer WG und gestalten selber ihren Wohnalltag

*die MitbewohnerInnen wählen können

*gleichberechtigt entscheiden können

*die notwendige Unterstützung dabei haben

*gleiche Rechte als MieterIn und MitbewohnerIn haben

*eigene 4 Wände mit Dusche und WC haben

*gegenseitig Hilfe geben und Austausch haben

*voneinander lernen, miteinander leben

*sich von der Familie ablösen können und trotzdem kontinuierlichen Kontakt und Austausch mit ihr haben

*Beteiligung am Leben der Wohnumgebung

*freie Wahl von Urlaubsgestaltung, Wochenende und Freizeit

## Inclusive living in Vienna

Neira-Zugasty, Helga

Living does not mean only “to have a roof above your head“, it means more: safety, freedom and dignity.

Living for handicapped people means additionally no barriers, diversity, free choice of decisions and the right of participation in the society on equal terms. Paragraph 19 of UN convention, article 19a specifies the right to choose where and with whom one wants to live.

The organization “ich bin aktiv“, founded by a group of parents, implements a concept of housing where people with and without handicap can live together in a community. They run their daily lives jointly and participate in a creative way with the surrounding society.

This requires:

Manageable guidelines,

Assured legal conditions

Supporters from the social chart of each handicapped member of the community

Planning of the living area according to the demands.

This way a real inclusive culture of relation can grow.

Relevant experience in Germany shows, that the constellation of four persons with needs of support and four persons without can organize their living community most effectively. Each community member participates according to his/her possibilities and capacities. Such an individual approach provides a high level of self-decision for handicapped people to manage their own life.

Currently we provide information for and develop cooperation with relevant governmental authorities. This process is well on its way.

## Maßnahmen zur Inklusion

Nyqvist Cech, Berith

Ziel: 6 Personen mit IB wünschten sich in die Gesellschaft einbezogen zu werden. Das wurde durch Gruppenarbeit mit den Themen ihrer Forschungsfragen umgesetzt.

Methode: Die Teilnehmer besprachen erlebte Situationen. Wir setzten dort ein, wo Probleme auftauchten. Diese berichteten Probleme wurden Teil unserer Forschung und des lebensverändernden Prozesses. Meistens waren diese Probleme von sofortiger Wichtigkeit für die Gruppe. Die gesammelten Daten wurden von der Gruppe reflektiert und diskutiert. Dabei fanden wir vier Schritte der Veränderung. Diese waren: Wissen, Gefühle, Willensäußerung und eine gemeinschaftliche Maßnahme.

Ergebnisse: Die Teilnehmer wissen, wie es sich anfühlt ein Outsider und ausgegrenzt zu sein. Sie erfuhren in ihrem Leben ein Machtmangel, Angriffe und Scham. Allerdings fühlten sie sich ebenso stolz und selbstbewusst.

Schlussfolgerung: Diese Methode kann Menschen dabei helfen ihr Selbstwertgefühl zu verbessern (empowering), wenn sie wie oben beschrieben verwendet wird. In Zusammenarbeit mit Personen mit Beeinträchtigungen und einem Wissenschaftler.

### Actions for Inclusion

Nyqvist Cech, Berith

Aim: Six people with intellectual disabilities wished to feel included in society. That was done by working with their research-questions in groups.

Method: The participants reflected and discussed experienced life situations. We started where problems appeared. These problems told became part of our research and life-changing process. Often these problems were of immediate importance for the group. The data we collected together was discussed and reflected in the group. Here we found four steps towards change. Those were: knowledge, feelings, expression of will and a collective action.

Results: The participants have experienced feelings of being outsiders, being exposed, lack of power, offence, and shame; but also feelings of pride and self-esteem.

Conclusion: This method can make people grow in self-esteem (empowering), when used like this, together with people with intellectual disabilities and a researcher.

Most of us reading this would agree that it makes sense that people whether they have high support needs or not, would want to live in their own home.

## Inklusives Leben im Messequartier Graz - Seien wir realistisch: Inklusion ist möglich

Paier, Frank & Staskiewicz, Mark

Der neue Wohnverbund der Lebenshilfe, bestehend aus zwei Wohnungen und zwei Wohngemeinschaften, liegt mitten in einer großen Siedlung. Hier leben Hunderte Menschen – im Zentrum der Stadt Graz.

Das Besondere am Leben im Messequartier ist die gesellschaftliche Vielfalt. Neben unserem Wohnangebot für Menschen mit intellektueller Beeinträchtigung gibt es ein traditionelles Wohnungsangebot und Wohnmöglichkeiten für SeniorInnen, ein Studentenwohnheim, einen Kindergarten, Arztpraxen, ein Café, ein Fitnessstudio, einen Post-Shop und weitere Gewerbeflächen.

Das Besondere am Messequartier ist eine Interessengemeinschaft der Nachbarschaft (IWM). Wir sind Mitglied dieses Vereins.

Gemeinsam organisieren wir Feste und andere Aktivitäten.
Highlights waren das gemeinsame Sommerfest mit 250 BesucherInnen und unsere Präsentation, der Tag der Lebenshilfe, mit 50 Gästen. Es kam zu Gesprächen, zum Austausch und zu gegenseitigen Einladungen. Wir Menschen mit Beeinträchtigung und unsere BegleiterInnen aus dem Lebenshilfe-Wohnverbund stehen nicht am Rande, sie sind Teil der Siedlungsgemeinschaft.

Wir haben von Anfang an versucht, Inklusion zu leben.

- haben die NachbarInnen mit einem Flyer und persönlichen Gesprächen über unseren Einzug informiert,
- haben Kontakt zu NachbarInnen, anderen sozialen Trägern, Gewerbebetrieben sowie Vereinen gesucht,
- sind dem Interessenverein der Nachbarschaft beigetreten,
- haben NachbarInnen zu unserem Fest eingeladen,
- nehmen am Stammtischen der Nachbarschaft teil,
- haben gemeinsam Feste und Veranstaltungen organisiert und Mitverantwortung übernommen.

Fazit: Es gibt viele Ressourcen in der Nachbarschaft und viele Möglichkeiten, Inklusion zu leben. Darüber wollen wir berichten.

## Integrated Living at Messequartier Graz – Let’s be realistic: Inclusion is possible.

Paier, Frank & Staskiewicz, Mark

The new Wohnverbund (Living Community) Lebenshilfe, consisting of two flats and two flat-sharing communities, is located centrally within a big residential area. Hundreds of residents live here – in the centre of Graz.

What makes life at Messequartier (MQ) special is the diversity of the community. It offers people with learning disabilities as well as retirees the opportunity to live in a common residential area. The MQ is further locating a student home, a kindergarten, doctor’s surgeries, a café, a fitness studio, a post office, and additional industrial real estate.

There is a Community of Interest of the Neighbourhood at the Messequartier – we are part of this community.

Together we organize festivities and other activities. Special highlights so far were the Summerparty with 250 attendants, and our presentation, „Der Tag der Lebenshilfe“ (The Day of Lebenshilfe), with 50 guests. That offered the opportunity for conversations, exchange of opinions and mutual invitations.

At the Lebenshilfe Wohnverbund we, the people with learning disabilities, and our assistants, are not located on the margins of the society but are part of the resident‘s community. From the beginning onwards we tried to live Inclusion.

We have

- Informed our neighbours both with leaflets and in person about our moving in
- Tried to maintain contact to our neighbours, other social institutions, commercial operations, and other communities
- Joined the Community of Interest of the Neighbourhood
- Invited neighbours to our festivities
- Been taking part at regular meetings of the neighbourhood
- Organized festivities and events and have thus accepted communal responsibility

Conclusion: There are many resources in our neighbourhood and many possibilities to actually live Inclusion; we would like to tell you about them.

## Kurzfilm: Wege zur Inklusion

Paier, Frank & Staskiewicz, Mark

Es soll ein Film der Lebenshilfe-GUV gezeigt werden.

Im Film werden Menschen mit intellektueller Beeinträchtigung, Assistenten, Nachbarn etc. gezeigt. Sie erzählen was ihnen zur Inklusion einfällt. Der Film umfasst alle Lebensbereiche, von Arbeit bis zum Wohnen.

Der Film geht 5:36 Minuten

http://www.youtube.com/watch?v=H-VkQ5hQNyY

### Short Film: Wege zur Inklusion (Ways to Inclusion)

Paier, Frank & Staskiewicz, Mark

A film of Lebenshilfe-GUV about people with learning disabilities, their assistants and neighbours will be shown. In it, they discuss their ideas concerning Inclusion.

The film covers all aspects of life, such as working and living.

It lasts 5.36 min.

http://www.youtube.com/watch?v=H-VkQ5hQNyY (german)

## Erwachsensein und Erwachsenwerden von Menschen mit Lernschwierigkeiten

Postek, Natalia

Über das Erwachsensein und Erwachsenwerden von Menschen ohne Lernschwierigkeiten gibt es bereits viel Wissen. Bis jetzt hat sich aber niemand angeschaut wie Menschen mit Lernschwierigkeiten die Themen Erwachsenwerden und Erwachsensein sehen. Es ist aber wichtig zu wissen wie sie die Themen sehen. Wenn man weiß wie sich Erwachsenwerden und Erwachsensein für sie gestaltet, kann man auch richtige Unterstützungsangebote entwickeln.

In werde in meiner Rede deshalb auf drei Fragen eingehen:

- Wann fühlen sich junge Menschen mit Lernschwierigkeiten Erwachsen?
- Was bedeutet Erwachsensein für junge Menschen mit Lernschwierigkeiten?
- Wer und war unterstützt sie auf ihrem Weg ins Erwachsensein?

Um diese Fragen zu beantworten, habe ich 25 junge Menschen mit Lernschwierigkeiten befragt. Ich habe sie zu ihrer Lebensgeschichte befragt. Ich habe mir ihre Erzählungen und ihre Lebensgeschichte genau angeschaut.

Ich habe gehört, dass es Menschen mit Lernschwierigkeiten wichtig ist als erwachsene Menschen gesehen zu werden. Ich habe herausgefunden, dass Erwachsensein heißt über Dinge nachzudenken, die einem wichtig sind. Es heißt auch mit anderen über die Dinge, die einem wichtig sind, sprechen zu können. Junge Menschen mit Lernschwierigkeiten fühlen sich mehr als Erwachsenem, wenn sie angenommen werden.

## Adulthood and the transition to adulthood of young people with learning disabilities

Postek, Natalia

There is already a lot of knowledge about the adulthood and the transition to adulthood of young people without learning disabilities. Up to the present just a few studies exist about the experiences and views of adulthood and the transition to adulthood of young people with learning disabilities. Yet it is important to have knowledge about this.

With the knowledge about the views and experiences of adulthood and the transition to adulthood of young people with learning disabilities good support offers can be developed.

In my speech I will talk about three questions:

- When do young people with learning disabilities feel like adult persons?
- What does adulthood mean for young people with learning disabilities?
- What support do they get at their transition to adulthood?

To answer these questions, I have made interviews with 25 young people with learning disabilities.

I asked them about their life story. Later I have analysed their experiences and their life story.

I have found out that it is important for young people with learning disabilities to be seen as adults. I have discovered that adulthood means for the young people, to think about important things in their lives. It also means to talk with others about things that are important for you. Also young people with learning disabilities see themselves as adult persons when they gain acceptance.

## Eine Selbstvertreterin erzählt, was sie will, damit Gesetze auch umgesetzt werden

Rahm, Mirjam & Braunstein, Nicole & Fall, Petra

Was wollen wir?

- Alle sollen wissen, was Inklusion ist. Sie sollen auch wissen, dass es Gesetze dazu gibt.
- Wir möchten die UN-Behindertenrechtskonvention erklären. Wir möchten auch schwierige Wörter wie Inklusion und Normalisierung erklären.

Die Konvention ist eine Vereinbarung über die Rechte von Menschen mit Behinderung. Diese Vereinbarung gilt schon in vielen Ländern.
In der UN Konvention steht: alle Menschen haben dieselben Rechte. In der Schule, in der Arbeit und auch sonst überall.

Dafür gibt es ein schwieriges Wort: INKLUSION.
Inklusion heißt wörtlich: miteinschließen. Gemeint ist damit das Mittendrin-sein.
Viele Menschen reden aber noch immer von Integration. Integration heißt: es gibt Normale und es gibt Andere.
Das soll aber nicht so sein. Die UN Konvention sagt ja, es sind alle gleich.

Es stellt sich die Frage: Kennt die Gesellschaft INKLUSION nicht? Oder will sie es nicht wissen?
Die Selbstvertreterin hat Ideen, wie man Inklusion erklären kann. Und sie hat auch Vorschläge, wie man Inklusion leben kann.

Betroffene Menschen sollen bei allem, was sie betrifft, mitreden und mitbestimmen.

- Beim Machen von Gesetzen, in der Freizeit und beim Geld verdienen.

Das soll normal sein.
Das Wort dafür ist NORMALISIERUNG.

- Dann gibt es den gemeinsamen Kindergarten und die gemeinsame Schule.
- Dort lernt jedes Kind, was es noch nicht kann. Verschieden sein ist dann gut und wichtig.

Wir haben herausgefunden, dass Betroffene viele neue Ideen haben.
Sie kennen sich gut aus und sollen gehört werden.

## A self-representative talks about what she needs in Austria to put laws into practise.

Rahm, Mirjam & Braunstein, Nicole & Fall, Petra

We want that everybody knows about the laws that talk about inclusion.

We want to explain the meaning of the Convention of Rights of Persons with

Disabilities and the words inclusion and normalization. This UN Convention is an agreement to persons with Disabilities around the world.

It says: All people have the same rights: In school, at work and everywhere.

This word is INCLUSION.

It means to involve everybody, to be in the middle.

But INTEGRATION means: There are normal ones and others.

This shouldn't be, the convention says, every person is born equal and has the same rights.

So we ask: Don't the society know about it?

## Mein inklusives Leben mit Lernschwierigkeiten

Stadler, Johann

Ich spreche in meiner Rede darüber wie ich mit meinen Lernschwierigkeiten durch meine Schulzeit gekommen bin und ich dann verschiedene Ausbildungen gemacht habe, bis ich meine Arbeit als Selbstvertreter bei atempo gefunden habe. Diese ist sehr inklusiv da ich mit Kollegen zusammen arbeite die keine Behinderungen / Lernschwierigkeiten haben.

Außerdem erzähle ich, wie ich vom betreuten Wohnen bis hin zum selbstständigen Wohnen mit Wohnassistenz gekommen bin.

Abschließend erzähle ich aus meiner persönlichen Sicht, was Menschen mit Lernschwierigkeiten brauchen um an der Gesellschaft teilzunehmen und ein möglichst inklusives Leben zu leben.

## My inclusive life with learning difficulties

Stadler, Johann

I am going to talk about how I completed school as a person with learning disabilities, the different job trainings i went through until i finally got my job as a self-advocate at atempo.

It is an inclusive job where i am working with people who do not have handicaps or learning disabilities.

I am also telling about the long and difficult path from assisted accommodation to independent living with mobile living assistance.

I am closing my talk with a few things people with learning disabilities need to take part in society and live an inclusive life.

## Inklusives Forschungsnetz in Finnland

Tiihonen, Petra

Das Inklusive Forschungsnetz ist eine Gruppe von Menschen, die sich mit dem Leben von Personen mit Beeinträchtigungen beschäftigen. Dieses Netzwerk ist für alle interessant, die sich mit inklusiver Forschung beschäftigen: Selbstvertreter, Assistenten und Forscher.

Ziel: Informationsgewinnung über:

- Das Leben von Menschen mit Beeinträchtigungen
- Das Leben in der Gesellschaft
- Gesellschaftliche Dienste

Das Inklusive Forschungsnetz wurde 2010 gegründet. Zu Beginn boten wir Workshops zum Training inklusiver Forschung an. Nach diesen Workshops hat das inklusive Forschungsnetz Studien zu folgenden Themen durchgeführt:

- Menschenrechte
- Arbeitsfragen

In der Rede besprechen wir die Zusammensetzung der Gruppe und über die Studien.

Wir lernten, dass das Inklusive Forschungsnetz dabei hilft

- Sich über Hilfsmittel und Ideen des Lebenslanges Lernen auszutauschen
- Und das Bewusstsein von Rechten erhöht.

## Inclusive Research Network in Finland

Tiihonen, Petra

To share what I have learnt, I will use three examples of how a microboard has helped someone with high support needs to live in their own home. What you hear might be useful for you directly, or to support someone you care about.

Inclusive Research Network is a group of people who study the lives of disabled people. Network is for anyone interested in inclusive research: self-advocates supporters and researchers.

The aim is to gain information about:

- The lives of disabled people
- Living in the community
- Community-based services

The Inclusive Research Network was assembled in 2010. First we had workshops where we provided training on ways to do inclusive research. After the workshops the Inclusive Research Network made studies on

- Human rights
- Work-related issues

The speech will be about assembling the Network and about the studies.

We learned that the Inclusive Research Network is a good way to

- Share tools and ideas for lifelong learning
- Raise the awareness of rights

## Ein Eigenheim mittels einer kleinen (mirco) verbundenen Gruppe (board)?

Walker, Ellen

Die meister Leser dieses Abstracts würden damit übereinstimmen, dass Personen mit oder ohne hohen Unterstützungsbedarf wohl gerne in ihrem eigenen Zuhause wohnen würden.

Eventuell haben Sie schon den Begriff „Microboard“ in dem Titel bemerkt. Ein Microboard ist ein rechtlich anerkannte Dienstleistungs-Agentur, die normalerweise aus 5 bis 8 Personen besteht. Sie arbeiten mit Personen mit einer Beeinträchtigung. In diesem Vortrag geht es um Mircoboards. Was sie sind, wie sie funktionieren und was sie machen.

Im Rahmen meiner Doktorarbeit habe ich versucht herauszufinden was Microboards sind. Dazu habe ich mit 3 Microboards in Australien und 3 Microboards in Kanada zusammengearbeitet. Ich habe Menschen, die einen hohen Unterstützungsbedarf und ein Microboard besitzen, zugehört und sie beobachtet. Außerdem habe ich mit ihren Familien und ihren Microboard Kollegen gesprochen.

In meiner Präsentation möchte ich durch 3 Beispiele zeigen, inwieweit Microboards Personen mit einem hohen Unterstützungbedarf geholfen haben, alleine zu wohnen. Was sie in meinem Vortrag hören, kann ihnen eventuell direkt helfen oder aber sie können dadurch jemanden helfen, der ihnen wichtig ist.

## A home of your own using a small (micro) incorporated agency (board)?

Walker, Ellen

You might have spotted the term microboard in my title. A microboard is usually made up of five to eight people who come together to form a legally recognized service agency to work with a person with disabilities. This presentation talks about microboards – what they are, how they work, and what they do.

As part of my PhD, I have been doing research with three microboards in Australia and three microboards in Canada to help me understand more about them. I have listened to, and watched people with high support needs who have a microboard. I have talked with their family and microboard members as well.

## Symposium 1.1: Profound Intellectual & Multiple Disabilities

### Do switch press rates show progress towards contingency awareness for people with PIMD?

P. Thorpe

### Realization of education in care/nursing in daycare centers

### for persons with PIMD

N.-C. Chen, I.-S.J. Chen & Y.-Z. Wang

## Exploring quantity perception and non symbolic number representation in adults with PIMD

M.Chard, J.-L. Roulin & M. Bouvard

We don’t know if persons with profound intellectual disability and motor disability (persons with PIMD) are capable to understand number or to count. In order to offer better educational programs to these persons, we need to know:

- How can we evaluate the concept of number with persons who can’t speak and who can’t move objects with their hands?

- Are these persons able to make a difference between two quantities of objects (for example: between 5 spoons and 10 spoons)?

- Can they count?

We tried to evaluate these persons: we showed them many objects in different quantities and we looked how long they were watching them.

We found out that persons with PIMD can see that the number of objects between two sets is different, when there is not too many objects at the same time. But we think that they are not able to count exactly how many objects there are on these sets. We need to do more research to understand better how persons with PIMD deal with number and quantities in their daily life.

# Effectiveness and Sustainability of interventions designed to enhance the quality of interactions between staff and people with Profound Intellectual and Multiple Disabilities (PIMD): a systematic review of the literature.

J. Ware, J. Goldbart, E. Anderson & A. Tan

Aims

We wanted to find out if training staff to communicate better with people with profound difficulties is successful. We also wanted to know what helped the effects of the training to last.

Method:

We tried to find all the papers people had written about training staff on communication. We looked at what was good and bad about these papers.

Results:

We found twenty-two good papers. These papers tried to measure how well their training worked and whether the effects lasted. Fourteen of the papers were about services for adults with profound difficulties. Eight were about children. Most of the papers showed that training does have a good effect on staff. Only half of the papers looked at whether changing the way staff communicate affects clients.

Conclusions:

Training staff in how to communicate with people with profound difficulties can work well. But we need to know more about what helps the effects of training to last in the long-term. We also need more studies done in schools.

# Symposium 1.2 Assessments of Support, Adaptive Behaviour, Self-determination & Quality of Life

## ARC-INICO Assessment of Self-determination Scale. Psychometric properties and factorial structure

M.A. Verdugo, E. Vicente, M. Gómez-Vela, R. Fernández-Pulido & V. Guillén

Aim: Assessing and promoting self-determination is a key educational issue. In Spain, there are few instruments designed to assess self-determination of students with intellectual disabilities.

Method: The aim of this research is to analyze the characteristics of a new scale. We administered this new scale to a sample of 279 students with intellectual disabilities.

Results: The results suggest this scale works well.

Conclusions: This scale gives useful educational information about individual level of self-determination.

## Measuring significant limitations in adaptive behaviour

P. Navas, M.J. Tassé, R.L. Schalock, G. Balboni, S.A. Borthwick-Duffy, S. Spreat, D.M. Thissen, K.F. Widaman & D. Zhang

## Assessing Supports for Spanish Children with Intellectual Disabilities

V. Guillén , M.A. Verdugo, B. Arias, E. Vicente & V. Aguayo

Aim: Supports are really important in the life of a person with disability. We want to develop a scale to assess support needs in children with intellectual disabilities.

Method: We administered this scale to 814 children in Spain. We analyzed the characteristics of this new scale.

Results: The results show this scale works well.

Conclusion: This scale gives information about the support needs of children with intellectual disabilities.

# Assessing quality of life related personal outcomes to improve services and supports

L.E. Gómez, M.A. Verdugo, B. Arias & P. Navas

This study provides information about a survey to assess the quality of life of adults with intellectual disabilities. For example, the survey allows to know what things make them feel happy and sad, if they can spend their money and free time in the things that they like, if they are happy with their employment or activities, if they are allowed to take their own decisions, if they like the place where they live, if they get along well with other people, if they need more friends, or what are the areas in which they need more support and help. This survey is called the “San Martin Scale". The survey is made up of 95 items that are answered by a professional or relative who knows well the person with intellectual disability. This survey was made for 1,770 persons with intellectual disabilities from Spain. Their ages ranged from 16 to 77 years old.We found out that this survey is very helpful to assess quality of life and to provide useful information that helps professionals and families to give better supports to people with intellectual disabilities and then improve those aspects in which people show more discontent.

## Symposium 1.3 Attitudes Towards Children with IDD, Education and Teaching

### Teaching skills for children with intellectual disability

A.H. Hawach

### Typically developing preschool children's perception – understanding (attitude forming) towards children with disability

D. Roth

For inclusion to be successful the attitude of "regular children" towards children with disability has to be a positive one so that regular friendships and relationships can take place. To know what children think of other with disabilities we conducted this study. A measure to evaluate what preschool children's think towards preschool children with disability was developed. This measure asks questions on how the children think, how they feel, and how would they behave with children with disabilities. Children aged 5-6 years old participated (106 children). This was done in Israel. Strong relations between how the children think, how they feel and how they behave towards children with disabilities was found. Generally, the "regular" children had more positive attitudes toward children without disability. Children as young as preschoolers have definite attitudes/perceptions regarding disabilities. These ideas can be a strong basis for developing negative attitudes. Therefore it is very important to provide them with knowledge and information by the education systems as early as possible regarding issues relating to disabilities.

## ‘Inclusion’, ‘Integration’, ‘Special’: varying conceptual understandings and perceived training needs among teachers supporting children with disabilities in Sri Lanka

S. Hettiarachchi, M. Ranaweera & A. Das

## Experiencing history: treatment of people with learning difficulties during the National Socialist-era

B. Lindmeier

# Symposium 1.4: People with IDD Talk about College Experiences & Life-Long Learning

## The inclusive college experience: benefits, challenges and outcomes experienced by students with intellectual and developmental disabilities

S. Ryan

## Analysing qualitative interviews using I-Poems

D. Corby, L. Taggart & W. Cousins

Aim: The aim is to describe and explain the use of I-poems to help understand what people with intellectual disability have said about going to College.

Method: This research study involved asking people about their experiences in College. People had lots to say about their experiences but some needed help to explain what they meant with prompts such as "tell me more about that?" or " why did you love the classes so much?". To help understand what was really important to the people that were interviewed a Poem was made from their interview. This was done by taking each they began a sentence with the word "I" and making it one line of the Poem. Here is part of one Poem; I go there to college with friends I am happy in my course I like reading and writing I love to be able to read

Results: Poems made by writing out when people use the word "I" helps in understanding what was important to them about going to College.

Conclusion: Using examples of the Poems this paper talks about how Poems help to explain the experiences people had in college and what was important about those experiences.

## There is no age limit for learning

G. Petitpierre, G. Gremaud, A. Veyre & I. Bruni

## Inclusive Post-secondary Education: The university experience for people with an intellectual disability.

F. Rillotta, T. Rozengarten, J. Arthur & C. Mahar

We wanted to find out what people with an intellectual disability think about going to university. We asked people who are participating in a university program to tell us their expectations and opinions of university. We checked who has been coming to the university since the program started. We found out their age and if they are male/female. Adults with an intellectual disability who are doing the program at university answered questions, and told us what they thought at an interview/group discussion. The people who help them at university (mentors) also answered questions. They told us things like if being at university helped them to learn more and to feel better about themselves. People said that they did feel a bit better about themselves and they learnt a lot from university. Many of them made new friends and learnt to socialise. We think it is important for people with intellectual disability to go to university, because it helps them to be like other people without disabilities and it also helps them to learn a lot. More universities should help people with intellectual disabilities to attend.

# Syposium 2.1: Transitions and Adult Learning in People with IDD

## Transition to adulthood in Spain: perception of professionals on transition partnerships between services which support young people with intellectual disabilities.

M. Pallisera , J. Fullana, M. Vilà, M. Castro & C. Puyalto

We need information about the relation between services that support young people with ID in their transition to adult life. Concretely, we want to know what the professionals think about the relation about these services.

We make our study in Spain. We came up with interviews and questionnaires. We did the interviews and questionnaires many times with different professionals. They were asked about:

- their ideas about the transition to adult life
- the things people with ID learn at school and other services
- the collaboration between different professionals

We found out that there is not a good relation between services and professionals. Professionals that work with people with intellectual disabilities need to talk more between them. They need to agree on tasks and duties to do. We also found that they need to talk more with young people and their families.

## Simplify or complicate? Adults with intellectual disability as independent technology users: An eye-tracking study

J. Csakvari, M. Gyori & Zs. Varnagy-Toth

If we want to develop good and comfortable support in technology usage for people with intellectual disability, we have to collect information about their needs and barriers.
How long time do they need to find something on a computer screen?
How accurately do they find a dot or something else on a screen?
What type of task is the easiest and which is the most difficult during computer using?

We used eye tracking technique to measure eye movements. This technique is very simple, people just look at a computer screen and they scan the images or videos. They just do nothing else, and the equipment, which is in a little box under the computer screen, collects information about people's gaze. We showed three interesting tasks and did eye tracking with 38 people with intellectual disability and 38 people without intellectual disability.

We found that people with intellectual disability need more time to find things on screen, and sometimes tasks are too difficult to pay enough attention to them. We also found that people with intellectual disability have very different eye movement behaviours. This technique is very good to collect information about and is able to give useful help for all people.

## Dance as a conduit for informal learning of adults with Down syndrome

A.M. Mumford

# Symposium 2.2: Inclusion and Exclusion in Education

## Opportunities and challenges in inclusive education and disability: a case study of Zambia

M.S. Chirwa

## Cultural and societal barriers to inclusion in three continents

G. Biewer

## The Hinges of Exclusion. A woman´s biographical struggle for participation

T. Buchner

This paper is about the life story of a woman with learning difficulties. She had to go to a special school but wanted to learn in a regular school. Teachers and psychologists made her stay in special school. In her story, she describes her struggle for inclusion in education. The woman was not successful in changing to a mainstream school. But the stories shows her strength and resilience.

## Designing the least restrictive inclusive school environment

B. L. Hutchings

Aim:

School planners often talk about how to include students with disabilities in the same classes as students without disabilities. They sometimes do not talk very much about the school building, itself. This study looked at how school buildings can be built or changed to work well for students with and without disabilities.

Methods:

We went to 18 schools and spoke with teachers, school social workers and therapists, and students with disabilities about how the school building worked. We also went to classes and watched to see what worked well and what did not work so well for students with all kinds of disabilities. We took pictures of some of the schools that worked well.

Results:

We learned many ways that schools could be built to work better for students with different types of disabilities, including students with intellectual disabilities, physical disabilities and autism. We got many of these ideas from the people that used the school buildings each day, including students with different types of disabilities.

Conclusion:

We learned how schools could make it easier for students to focus, find their way from one room to another, see and hear what is going on, and work by themselves, in small groups or in large groups. As well as learning about the inside of the school, we also learned how to make the school grounds work better for everyone.

# Symposium 2.3: Inclusive Education

## Promoting social capital through inclusion in Swedish Schools

B. Persson & E. Persson

There is a need to analyse successful strategies to meet Swedish pupils' declining school results due to the 2012 OECD/PISA findings.

We need to know more about the effects of inclusive education for all learners. In a previous study we have followed a Swedish municipality that started a development work in 2007. The starting point was to give all students the opportunity to succeed in their regular classes by inclusive education. All kinds of ability grouping and special education groups were closed down. Three years later all students left lower secondary school with pass grades. All students went on to upper secondary school.

In this follow up study we have followed all pupils who left grade 9 in 2010 through their upper secondary schooling. Our analyses show that the work at lower secondry school had an impact on the young people's continuing education. They described a feeling of security in that they can set personal goals and have the ability to reach them. Students seemed to have a clarity about themselves, their strengths and their educational choices.

## Social Position of Children with Mild Intellectual Disabilities in Integrated Schools in Hungary

Á. Szekeres

The speech describes the position of children with mild intellectual disability in classrooms.

Participants were 400 pupils from the 4th, 5th and 6th grades. We used:
sociometric questions,
questionnaire about integration,
questionnaires for teachers, for special educators and for the children.

The position of children with mild intellectual disability is worse than that of their peers. Boys with mild intellectual disability like going to school better, than other boys. The disabled boys' emotional state is more positive in these classes. Children with mild intellectual disability cannot meet the school requirements to such an extent that the others. Children with mild intellectual disability received fewer choices, than the non-disabled students in some questions (for example: Who is the most diligent pupil in the class?; Who do you like talking to? and so on).

Our results may help teachers in the integrative classrooms.

## Participation of disabled children in the Austrian school system

F. Brandstetter

## Inclusive education: logics and ambivalence

J.Ineland

# Symposium 3.1: Teaching Skills to Children with IDD

## Influence of computer intervention and video modeling multi-media on social-skill acquisition among students with intellectual disabilities

O.Hetzroni & I. Banin

Children with intellectual disabilities who learn in school often have difficulties in learning school and play rules for school during class and recess. We wanted to see if using videotapes of the children in the school and group activities would help children understand the rules better.

Four children learned how to play with a friend, how to enter without pushing, and how to ask for something and get permission for it. They videotaped themselves and worked in groups to learn how to solve the problems and learn the rules. They used the computer for watching the videos and played games to help them learn the rules.

All the children managed to learn the rules and used them correctly most of the time. They learned to behave better in school and taught other kids to do so as well. They liked playing with the computer and play the games.

## Teacher delivery of emotion-based social skills training to adolescents with a moderate intellectual disability: a novel whole-school approach to teaching social-emotional skills

B. Ratcliffe, M. Wong & D. Dossetor

## Psychomotricity as a Reading Access Facilitation Strategy for Children with Learning Disabilities

A. Almeida, H. Serra & J. Gonzalez

Purpose: We need to find strategies to help children with learning disabilities to read and it seems that using our entire body is the best way to do that.

Rationale: Reading is crucial to promote inclusion at school and in society.
We studied the influence of various factors (small movements, big movements, understanding of our body, sight, ability to tell left from right and understanding of time and space) on reading skill, using the Program for Promoting Psychomotor Development (PPPD) we created. Currently, scientists prefer to use strategies related to how we hear, but we can’t despise other ways of learning. The characteristics we mentioned may be affected in children with learning disabilities on reading. So, we propose a new focus on learning disabilities: learning to read with our entire body.

Summary: We expect that this perspective of learning can be more and more valued by scientists and other professionals in the field of Education, just because it’s more inclusive: it includes all the potential of the human body.

# Telling tall stories: the use of multisensory ‘story boxes’ based on children’s storybooks to improve vocabulary and narrative skills in children with intellectual impairment

S. Hettiarachchi & M. Ranaweera

# Symposium 3.2: Support for Teachers and Peers

## The importance of explaining autism to peers for promoting social inclusion and interaction in mainstream school classrooms

P. Molteni, L. d'Alonzo & M. Colombo

We wanted to have information about how teachers help peers in understanding autism and how they explain it to the class. For example, we collected information about:

- special inclusive activities;
- group interaction and friendship;
- how to explain the main aspects of autism.

We came up with observations, questionnaires and focus groups, involving 133 teachers from mainstream schools.

This work showed that:

- high school teachers don't think it is important explaining autism to the kid's classmates;
- after peers understand autism, they feel better with the autistic classmate;
- there is a better relationship between classmates after understanding autism.

We understood that explaining autism to peers is fundamental to promoting social inclusion and interaction in schools.

## Promoting social integration among mainstream and special school peers through a peer-mediated social integration programme

B. Lee, J. Teng & C. Kwek

We want students from a special education (SPED) school to experience what it is like to be in a mainstream primary school by making friends with students at that school. We also want the mainstream students to learn how to talk to and play with the SPED students.

We had three sessions for 9 SPED students and 9 mainstream students. Each session lasted half an hour. The students were aged between 9 and 11 years old. They played games and had snack together. The teachers guided the students when they needed help. We watched the students interact together to see if their social skills improved and wrote a Learning Story about it. We also spoke to the mainstream students to find out how they felt about the sessions.

We found out that 8 of 9 SPED students had improved in social skills. The mainstream students also enjoyed the sessions, even though talking to their buddies was not easy. They would like to take part in the programme again if there is a chance next time.

We hope that more programmes that allow both SPED and mainstream students to come together will be carried out in the future.

# Reliable Evidence Based Outcomes Optimization Technologies (REBOOT): technology infrastructures and decision-support to increase positive outcomes

L. Marshall & J.S. Zeiter

# Theme: Health: General Health and Specific Health Issues

## Symposium 1.1 Diabetes and Intellectual Disabilities

### The view and experiences of professionals caring for adults with intellectual disabilities and type 2 diabetes

M. Brown, S. Macrae, T. Karatzias, L. Taggart & R. Northway

### Understanding the potential of pre-diabetes screening to predict future type 2 diabetes among people with intellectual disabilities

P. McCallion, R. Carroll & M. McCarron

### A study protocol for a pilot RCT of a structured education programme (DESMOND-ID) for adults with intellectual disabilities and type 2 diabetes

L. Taggart, M. Truesdale-Kennedy, M. Carey, L. Stacey, P. Madelia, J. Scott, V. Coates, M. Brown, R. Northway, B. Bunting & M. Clarke

### Type 2 diabetes education for adults with intellectual disabilities

M. Truesdale-Kennedy, L. Taggart, M. Carey, L. Stacey, P. Madelia, J. Scott, V. Coates, M. Brown & R. Northway

# Symposium 1.2 Cognitive Functioning in People with IDD

## Context-specific memory in children with ADHD

K. Kerns & S.J. Macoun

When we remember things, we typically remember more than just what was said, but also remember who we learned something from and also when they learned it. These parts of memory are called contextual memory and different parts of the brain are used to remember the who/when part of memories than the memory itself.

In children with Attention Deficit Hyperactivity Disorder (ADHD), the parts of the brain that are important for the remembering who you learned something from and when you learned it are the same part of the brain that can cause the attention deficits.

We wanted to see if children with ADHD had more difficulty remembering who they learned new information from or when they learned it. We had children with and without ADHD remember some things that they were told by different people. Both children with and without ADHD could remember the things equally well, but the children with ADHD did a better job remembering who told them but did worse on remembering when they learned things. We discuss what this tells us.

## Prospective memory in traumatic brain injury and intellectual disability: relationships with working memory and memory awareness

C. Mateer

Aims: In everyday life, it is important to remember to remember to do things. For example, if you want to pick up milk on the way home, you need to remember to do that. This ability is called Prospective Memory (PM). Children and adults with brain related problems often have difficulty with PM.

Methods: In this study 20 adults with traumatic brain injury and 20 adults with no injury completed PM tasks on a game called 'Navigating Your Week' in which they were told to do certain tasks at a future time or when a hint was provided.

Results: People with traumatic brain injury had more difficulty remembering to do the tasks. They also had more difficulty when they were asked to hold information in mind for a short time (working memory). In the paper these results will be compared with people who have intellectual disabilities and with people who are old.

Conclusions: People with traumatic brain injuries and with intellectual disabilities, as well as people who are getting older have difficulty remembering to remember to do things. This is related to the ability to hold things in mind. The presentation will describe these relationships and also suggest strategies for how to compensate for and manage PM difficulties in everyday life.

## Source Monitoring in Children With and Without Fetal Alcohol Spectrum Disorders

J. Pei, K. Kully-Martens, J. Job & C. Rasmussen

Understanding how our memory works helps us to use it to the best of our ability. By better understanding memory functioning in people with disabilities, such as FASD we can better support them. For this project we were interested in how children with an FASD remember where they have learned information.

Do they remember:
· If it was something they saw in reality or they heard about (e.g. saw a house fire or read about the house fire in the newspaper (reality monitoring).
· Which friend provided information (external monitoring).
· Whether they said something or thought something (internal monitoring).

We worked with 19 children and found that with an FASD remember the source of the information best when it was reality monitoring, and have the most difficulty when asked to remember the internal source.

# Executive function and attention profiles in preschool and elementary school children with autism spectrum disorder and attention deficit hyperactivity disorder

J. Sinzig, I. Vinzelberg, D. Evers & G. Lehmkuhl

## Symposium 1.3 Longevity and Mortality in People with IDD

### Findings of the Confidential Inquiry into premature deaths of people with intellectual disabilities in England

P. Heslop, A. Marriott, M. Hoghton, P. Fleming, P. Blair & L. Russ

In England, a study looked at whether some people with intellectual disabilities (ID) are dying too soon. The study looked at all the deaths of all people with ID in an area of South West England. The deaths of 247 people with ID were studied. People with ID, on average, died sooner than people in the general population – for men this was 13 years sooner and for women it was 20 years sooner. Some of the people with ID could have lived longer. Good quality healthcare can help people with ID to live longer and healthier lives. Finding out what is wrong with a person when they become ill is especially important. It is also important to give people the right treatments. The study said that the quality of health and social care given to people with ID wasn’t always good enough. Poor quality care made some people with ID die sooner than they should have.

## Mortality Surveillance in Adults with Intellectual Disability: Findings from the United States

E. Lauer & A. Bonardi

Aim: This talk will discuss why and when adults with intellectual disabilities die using information from the United states. This information can help us understand how to improve health and reduce deaths for people that are still alive.

Methods: We used information about people who died in three state systems that provide supports to people with intellectual and developmental disabilities. We also looked at why and when people without disabilities died across the United States. This helped us understand if people with disabilities died from different causes or at different ages.

Results: More adults with intellectual disability die at younger ages than adults without disabilities. Fewer people with disabilities die from cancer than other adults without disabilities. More people with disabilities die from illnesses that they experience for a long time such as Alzheimer’s disease, and lung infections.

Conclusions: There are many reasons that people with disabilities die at younger ages than other adults. Some of these reasons may be things that can be improved with better health care. We will talk about examples where information about people who died was used to help improve the health or quality of life of people who are still alive.

## Understanding increasing longevity for people with intellectual disability: findings from New York State administrative data

P. McCallion, J. Hasting & M. McCarron

## To understand differing patterns of age of death by gender and level of intellectual disabilities for people with intellectual disability in Ireland

M. McCarron, C. Kelly, R. Carrol & P. McCallion

# Symposium 1.4 Family Involvement and Child Behaviour

## Family management ability among parents of children with Autism Spectrum Disorder

R. Hock, I. Kim & A. Kinsman

We need to have information about how parents manage their families and if parents do what doctors and therapists ask them to do to help their children. For example, we need information about: How are parents raising children with autism spectrum disorder managing their families? Is it easier for parents who are better at managing their families to do what doctors and therapists ask them to do? Do differences in what parents have (support from family and friends, medical care) and differences in their children help parents manage their families? We came up with a survey to answer these questions. We sent it to parents with children with autism spectrum disorder by mail and email. 274 parents returned the survey to us. The speech will be about this survey. We found out that helping parents better manage their families could help them do what doctors and therapists ask them to do. We also found out that differences in children and the support parents have from their spouse, friends, and family members could help parents better manage their families.

## How to engage fathers to increase their involvement while taking part in an early intervention-based family support programme

G. Toth, Y. Ozaki & M. Saito

## Parenting young children with an intellectual disability: parenting practices, relationships and children's behaviour problems

V. Totsika, R.P. Hastings, E. Emerson & D. Vagenas

We wanted to understand better what parents do with their young children. A survey done in the UK has information from thousands of very young children. We looked at families with a child with an intellectual disability. We described the things parents did with their children when they were 3 years old: what parents did when children misbehaved, how noisy the house was, and whether the parents and children got on well with each other. When parents had a warm, positive relationship with their 3-year-old child, the child behaved better at 5 years. When the relationship was not very warm, children misbehaved a bit more. It is important to help parents and children to have a warm, positive relationship with each other.

# The impact of child characteristics on parental perceptions of challenging behaviour

J. Waite, C. Oliver, J. Moss, K. Eden & L. Wilde

## Symposium 1.5 Bereavement and People with IDD

### Exploring Responses to Bereavement and Loss with People with PIMD Using Cultural Resources

B. Fornefeld

Cultural offers like poems and stories help people with PIMD to deal with bereavement and loss. Nearly all people with PIMD cannot speak. They often react on bereavement and loss with their body. It is difficult to recognize their feelings and to accompany them appropriately. Usual methods of bereavement support are not suitable for this group of persons. We try to identify the causes of their bereavement behavior. Then, poems and stories of bereavement are edited. Now they can be experienced by the people with PIMD with all senses. Video analyses and observation forms prove whether their well-being increases.

First results show: Mourning people with PIMD can be involved in cultural offers. These offers help them to relax.

### Creation of a bereavement learning resource and the benefits of collaborative working in this process

L. Lambe, H. Young & B. Garrard

### Using a multi-sensory memory box to explore bereavement and loss issues with a young woman with profound intellectual and multiple disabilities

H. Young, B. Garrard & L. Lambe

## 1.6 Physical Health Issues and People with IDD

### Health problems in adults with Profound Intellectual and Multiple Disabilities (PIMD): Parents' insights into diagnosis, treatment and management

D. Chadwick

What we wanted to find out:
We need to know more about how people with intellectual disabilities and other health problems let their families know they don’t feel well.

We need to know:
how parents notice if their son or daughter is poorly
how people with intellectual disabilities and other health problems and their families are treated in health services, for example the hospital
what families think would improve health services

What we did:
We asked family carers about these things. This talk will be about what they told us.

What we found out:
Some family carers found it hard to see when their son or daughter was ill. Others could see when their family member felt ill but found it hard to tell why they were ill. Some people working in health services, for example hospital doctors, helped people and their families a lot. Others were not as helpful and sometimes didn’t believe that the things that the family had seen did tell them that someone felt ill. Getting people with intellectual disabilities and other health problems good health care can be hard.

## Guidelines of the European Association of Intellectual Disability Medicine on physical and mental health issues

F. Ewals, P. Martin, T. Dorn & R. Banks

## Physical Health Issues in Persons with Severe or Profound Intellectual and Multiple Disabilities: a Systematic Review

E.A. van Timmeren, C.P. van der Schans, H.M.J. van Schrojenstein Lantman-de Valk & A. Waninge

People with severe or profound intellectual and multiple disabilities experience a wide range of complex health problems. We need to have more information about these health problems. We searched in the literature to find answers to the following questions:

- What kind of health problems do people with severe intellectual and multiple disabilities have?
- And how often do they experience these health problems?

After searching in literature and reading a lot of papers, we found out that 30 studies were suitable to find an answer to our questions. We analyzed these 30 papers accurately.

The speech will be about the analysis of the papers and the health problems we found in the literature. We will discuss the results with the audience. The results will be used for further research. Our ultimate goal is to develop a screeningsinstrument of health problems for adults with severe or profound intellectual and multiple disabilities.

# Symposium 1.7 Health and People with Severe and Profound IDD

## Assessment of pain in persons with profound intellectual and multiple disabilities: analysis of reliability and validity of the REPOS

A. Bruns, E. Kreukniet, W. Post & A. van der Putten

## Developing an online resource toolkit to improve practice in the delivery of invasive procedures to people with profound intellectual and multiple disabilities

J. Hogg

## The actual condition of medical care at home for persons with medically-dependent severe motor and intellectual disabilities in Japan

T. Matsubasa, K. Sawano, M. Shiota & H. Mitsubuchi

## Symposium 1.8 Behavioural Phenotypes and People with IDD

### People or trains? Visual preference for social versus non-social information in genetic syndromes

H.R. Crawford, J. Moss, C. Oliver, T. Elliott, G.M. Anderson & J.P. McCleery

### Refining the profile of social and sensory reinforcement in angelman syndrome

M. Heald, D. Adams, E. Walls, J. Trickett & C. Oliver

### The relationship between executive function and repetitive behaviour in cornelia de lange syndrome

V. Johnson, S. Beck, J. Moss, J. Waite, C. Stinton, K. Eden, L. Powis, R. Dowlen, L. Groves & C. Oliver

### Atypical preference for adult social contact in children with smith-magenis syndrome

L. Wilde, D. Silva & C. Oliver

## Symposium 1.9 Foetal Alcohol Spectrum Disorder

### Intellectual Ability and Adaptive Functioning in Individuals with FASD: Are The Related?

K.A. Kerns & J. Pei

Individuals whose mothers drank alcohol with they were pregnant can have a disorder called Fetal Alcohol Spectrum Disorder (FASD). Along with this they also often have an ID, though some people with FASD have normal intellectual abilities.

More importantly all individuals with FASD typically needs support to be able to complete every day skills, called adaptive behaviors.

We have done a review of studies investigating the relationship between intelligence and adaptive behavior comparing people who have FASD and have either average intelligence or ID.

We found that while they differ in intellectual ability, in many other important abilities such as attention and executive function they have similar problems.

Some studies even show that children with an ID do better in everyday skills than those with average intellectual abilities.

We conclude that for individuals with FASD the level of disability is more related to having FASD versus measures of intellectual ability.

## Adolescents with FASD – Getting to Graduation: Inclusive Education in Action

J. Pei & C. Poth

Fetal Alcohol Spectrum Disorder can be a significant challenge in the teen years, as expectations for independence grow. It is during the teen years that youth with Fetal Alcohol Spectrum Disorders experience more difficulties than is normal for this age period. For example, reported problems include trouble with the law, mental health issues, increased drug and alcohol abuse, and increased risk of suicide. To help prevent these problems support in these teen years is very important. In an effort to support these youth, the Wellness, Resiliency and Partnerships (WRaP) project was created. Through this project “success coaches" work with schools to help prevent these problems. This is done by focusing on building on the youth’s strengths and providing supports that create opportunities for greater success.

In this presentation we will:
- Explain the needs of this population
- Describe the WRaP project
- Talk about the positive impacts of the program, such as increased attendance and course completion, decreased expulsions from school, and improved social functioning in school.

## Process Specific Interventions in Children with FASD: Inclusive Education in Action

K. Kerns, J. Pei, S. Macoun, C. Rassmussen & M. Hutchinson

Children whose mothers drink alcohol during pregnancy have problems with being able to pay attention and with remembering information when they can’t write it down. This causes difficulties both in school and at home.

We wanted to create a treatment that would help them be able to do better on these things. People who have had brain injuries also have a hard time with attention and remembering information, and researchers have found certain kinds of brain exercises improve their abilities.

In order to improve, requires quite a lot of practice. We created these kinds of exercises for children, as part of a computer game. As it is important to practice frequently we had these special games included as part of the children's schoolwork.

Their educational assistants helped them to play the games and helped them come up with ways to get better.

At the end of the study the children had improved on the abilities practiced in the games, both on tests in which they had to pay attention and remember, and according to the reports of their educational assistants and parents.

## Mathematics Intervention for Children with Fetal Alcohol Spectrum Disorder

K. Kully-Martens, J. Pei, J. Kable, C. Coles, G. Andrew & C. Rasmussen

Math is an important skill in daily living activities, yet children with an FASD have particular difficulty with math. The Math Interactive Learning Experience (MILE) is an intervention for improving underlying skills important for math.

In this study we used MILE with children with an FASD to see if it would improve math skills when used in a school setting. We were also interested in seeing if the skills related to math (e.g. how I understand shapes) were better after the intervention. We worked with seventeen children, who were four to ten years old, for six weeks.

We found that the kids who completed MILE did much better in math at the end of the intervention, when compared to a group who did not receive the intervention. Some of their underlying skills also improved. As a result we see this intervention as beneficial for children with an FASD

# Symposium 1.10 Healthy Living and Health Promotion

## Staffs' knowledge and attitudes towards the health promotion needs of people with intellectual disabilities

L. Hanna-Trainor, L. Taggart, E. McCaughan & G. Adamson

## Exploring the theoretical frameworks of health promotion for people with intellectual disabilities

L. Hanna-Trainor, L. Taggart & E. McCaughan

## Healthy living according to adults with intellectual disabilities, a thematic analysis of focus groups: "First, you need to know what is healthy for you!"

N.M.J. Kuijken, J. Naaldenberg, M.W. Nijhuis-van der Sanden & H.M.J. van Schrojenstein- Lantman de Valk

Living healthy can make you feel better. For example, you can eat healthy foods or exercise regularly. This can be difficult for people with intellectual disabilities. Maybe they need some help to exercise. Or maybe they have different interests than their caregivers. To help people with intellectual disabilities to live more healthful, we asked them about their experiences.We did 5 group interviews with people with intellectual disabilities in the Netherlands. In each group, 4 or 5 people talked together about what healthy living means for them. They also gave each other tips about healthy living. We interviewed 21 people with intellectual disabilities in total. People with intellectual disabilities told us that:
-Healthy living is not only about eating healthy and exercising;
-Friends and caregivers can support you if you want to live healthy;
-Living healthy is easier when it is fun or when you really want to do it.
We learned that 'feeling healthy’ does not mean the same for everyone. Because of this, living healthy is different for many people as well. If you know what people with intellectual disabilities think about healthy living, you can better support them to live more healthful.

## Adapted ‘healthmatters program’: promoting healthy lifestyles in individuals with an intellectual disability

L. O’Leary, L. Taggart & W. Cousins

## Symposium 1.11 ASD: Screening and Diagnosis

### Music-based autism diagnostics (MUSAD): a newly developed diagnostic measure for adults with intellectual developmental disabilities suspected of autism

T. Bergmann, T. Sappok, M. Ziegler, S. Dames, A. Diefenbacher & I. Dziobek

### The diagnostic behavioral assessment for autism spectrum disorder – revised: a screening instrument for adults with intellectual disability suspected of autism spectrum disorder

T. Sappok, I. Gaul, A. Diefenbacher, T. Bergmann, I. Dziobek, S. B€olte & M. Heinrich

### Validity of the social communication questionnaire in adults with intellectual disabilities and suspected autism spectrum disorder

T. Sappok, A. Diefenbacher, I. Gaul & S. B€olte

# Screening for autism spectrum disorder in specialist mental health and forensic settings

L. Underwood, J. McCarthy & E. Chaplin

We looked at two ways of finding out whether someone has autism. We looked at two questionnaires for autism. One questionnaire was called the social communication questionnaire. We used the social communication questionnaire with 121 people with intellectual disability. The other questionnaire was called the autism quotient. We used the autism quotient with 240 prisoners. We tested how good the questionnaires were at telling us whether someone has autism. The questionnaires did not find everyone with autism. We need better questionnaires to identify people with autism. We need special questionnaires for people with intellectual disability. We need special questionnaires for people in prison.

## 1.12 Health and PIMD

### Usage of Grading System of Epileptic Control (GSEC) for PIMD in Maria Wufeng Caring Home

H.-T. Chuang, T.-H. Chiang, C.-T. Tsai & S.-F. Tsai

We have developed a system for our service users in Maria Wufeng Caring Home. The system is called the Grading System of Epileptic Control. It is used to check the results of our epileptic treatment. There are 6 grades in the system, namely G0, G1, G2, G3, G4 and G5. The higher the grade, the more frequent and risky the epilepsy is. Higher grades also mean higher scores and poorer control of epilepsy. Service users with higher grades are referred to doctors for regulation of medication. We have used the system in the past 5 years. 3 out of 10 of epileptic attacks have been reduced. This system is an useful tool to monitor and improve the outcomes of epileptic control.

## Oral care for persons with profound intellectual and multiple disabilities

S.-T. Huang

## Bone health in individuals with profound intellectual and multiple disabilities

C.-L. Lin & Y.-F. Su

## Delivery of daily medical care for persons with profound intellectual and multiple disabilities: practice in various countries

S. Sone

## Symposium 1.13 Behaviour Problems, Mental Disorders and the Family

### Behavior problems and mental disorders in adolescents with autism spectrum diorder, intellectual disability, or typical cognitive development I: group comparisons

B. Baker & J. Blacher

### Behavior problems and mental disorders in adolescents with autism spectrum diorder, intellectual disability, or typical cognitive development II: collateral effects on parents

J. Blacher & B.L. Baker

### Longitudinal predictors of maternal depression in mothers of children with and without intellectual disabilities

S. Zeedyk, J. Blacher & B.L. Baker

### Discussant: international perspectives

P. Walsh

## 1.14 Primary Healthcare and Health Screening

### Preventive health screening  for people with intellectual disabilities-a systematic review

E.J. Bakker-van Gijssel, J. Naaldenberg & H.M.J. van Schrojenstein-Lantman de Valk

Aim: People with Intellectual Disabilities (ID) often have problems with their health. Sometimes it is difficult to recognize these health problems and treat them. Research showed us that preventive health screening for people with ID can be helpful. Worldwide there are different preventive health screenings instruments. We want to find all these instruments and give an overview of them. In this way we can learn from the experiences other researchers had.

Method: We searched in 4 different databases of scientific literature for research published between 2000 and 2013 to find all these instruments.

Results: The presentation will show all the preventive health screenings instruments found. We hope to give answers to the following questions:

1. For which group of people with ID was the instrument used or developed?
2. Which items are in the preventive health screenings instruments?
3. Who performed the preventive health screening?
4. What was helpful or not helpful when they used the instrument?

Conclusion: The answer to all these questions will help us to develop new preventive health screening instrument in a new context, for example in another country.

## An outpatient clinic for adults with down syndrome: results and recommendations

A. Coppus

## Organisation of out-of-hours care for people with intellectual disabilities: a survey of service providers

M. Heutmekers,J. Naaldenberg, W.J.J. Assendelft & H.M.J. van Schrojenstein Lantman-de Valk

Medical care outside working hours is good, safe and accessible for the general population in The Netherlands. But we do not know if it matches the special needs of people with intellectual disabilities. Or how we can improve this care. We need information about:

- How this care is organized?
- What goes well?
- What problems are there?

We invited all service providers for people with intellectual disabilities in the Netherlands to help in the study. We phoned them to ask a list of questions. We will present an overview on medical care outside working hours for people with intellectual disabilities. The overview will help to improve this care.

## Health information exchange in general practice care for people with intellectual disabilities – a qualitative study on the patient perspective

M. Mastebroek, J. Naaldenberg, A.L.M. Lagro-Janssen & H.M.J. van Schrojenstein Lantman de Valk

When people with intellectual disabilities visit their family doctor, it is important that the doctor receives information on the patient's health. The doctor needs this information to know what is wrong and what should be done about it. People with intellectual disabilities may have problems in telling the doctor what is wrong, and in understanding or recalling the doctor's words. We interviewed people with intellectual disabilities.We asked for example: Does your doctor understand when you explain what's wrong? What do carers do to help you and your doctor talk with each other? We found that there were many groups of answers, all having to do with different subjects. For example:Thoughts and emotions: how you feel and what you think when you see your doctor has influence on how well you can talk with each otherPreparing yourself before a doctor's visit: writing down what you want to ask can help you in talking with your doctor We now know more on how people with intellectual disabilities share health information with their doctor and carers. This can help us to find solutions for problems in sharing information.

## Towards tailored primary health care for persons with intellectual disabilities

H.M.J. van Schrojenstein Lantman-de Valk & J. Naaldenberg

# Symposium 1.15 Health and People with IDD

## Exposure of Children with Developmental Delay to Social Determinants of Poor Health: Cross Sectional Study

E. Emerson & P. Brigham

Some children with intellectual disabilities have poor health. We want to know why. We looked at some of the bad things that can happen to children. Things that can make them poorly. Children with intellectual disabilities are much more likely than other children to have bad things happen to them. That is one of the reasons they have poor health.

## Obesity and Health Behaviours of British Adults with Self-Reported Intellectual Impairments

J. Robertson, E. Emerson, S. Baines & C. Hatton

We wanted to find out if British people with intellectual disabilities are more likely to be obese than other people in Britain. We also wanted to see if they are more likely to do some of the behaviours that can be bad for health, such as smoking. We did this by looking at information collected by a big British Survey called Understanding Society. This involved over fifty thousand people. We found that just over 500 of these people might have intellectual disabilities. We compared people we thought might have intellectual disabilities with the other people in the survey. We looked at whether people were obese. We also looked at exercise, diet, alcohol use and smoking. We found that more people with intellectual disabilities were obese, inactive, smoked, drank alcohol daily and had poor diet than other people in the survey. We looked to see if any of these differences were to do with age, gender, or poorer living conditions. We found that some of the differences might be due to poorer living conditions. We think that higher levels of obesity, and behaviours that are bad for health, are part of the cause of the poorer health of people with intellectual disabilities.

## Perceptions of neighbourhood quality, social and civic participation and the self-rated health of British adults with intellectual disability

C. Hatton, E. Emerson, J. Robertson & S. Baines

# Gaps in the Evidence Base on the Health or Healthcare of People with Intellectual Disabilities: A Review of Systematic Reviews

J. Robertson, C. Hatton, E. Emerson & S. Baines

We wanted to find out what work has been done on the health or healthcare of people with intellectual disabilities. This was to see what topics we know a lot about, and what we do not know much about. This was to help people decide what work they should do in the future. We did this by looking at 'systematic reviews'. A 'systematic review' is a piece of work that carefully looks at all the research on a topic. We looked at reviews that came out from 2008 to 2013. We put all of the reviews into groups based on their topic. We looked to see which topics had most reviews done. We also looked to see which topics had not had reviews done. We found nearly a hundred reviews. Over half of them were about mental health or behaviour problems. There were no reviews found for some topics that are important to the health of people with intellectual disabilities. We think that a lot of systematic reviews have been done on mental health and behaviour problems. More work needs to be done on other topics that are important to the health of people with intellectual disabilities.

# Symposium 1.16 Cognitive Skills, Decision-Making and ID

## A guideline to increase the reliability of self-reports of people with mild intellectual disabilities

J. Douma, X. Moonen, L. Noordhof & A. Ponsioen

Background: People with mild intellectual disabilities (MID) can perfectly tell us how they feel and what they think, but still only few questionnaires are especially made for them. Therefore, we use questionnaires meant for people without MID. But, because the language often is too difficult, it is harder for them to answer the questions.

Aim: To learn why people with MID have more problems answering these questionnaires (besides language problems) and what we can do to make the questionnaires easier to answer.
Method: We studied the literature and we interviewed people with lots of experience interviewing people with MID.

Results: We wrote a guideline for professionals who make questionnaires or who ask the questions to people with MID. The guideline gives information about an MID and, more importantly, it tells professionals what they can do to help people with MID to have a voice in diagnostic and scientific research.

Conclusions: We believe that when professionals use this guideline to make questionnaires or to ask people with MID questions, more people with MID will be able to really tell us how they feel and what they think.

## IQ, the Flynn effect, mental illness and intellectual disability: a cognitive reserve hypothesis

T. Florio & J.N. Trollor

## Healthcare inclusion and everyday choices: an experiential perspective from adults with ID and their carers

M. Terras, D. Jarrett & M. Ferguson

## Computerised training as a primer for assessing cognitive mediation skills in people with intellectual disabilities

L. Vereenooghe, S. Reynolds, L. Gega & P.E. Langdon

Therapy helps people to better understand their thoughts and feelings. Some people find these things difficult and may need help in understanding therapy. This talk is about a computer programme that may help people in preparation for therapy. Over sixty people with intellectual disabilities used a computer programme.

They completed three steps:

Step 1: People were given two tasks. Task A showed pictures of a situation and a thought. People were asked to select how they would feel. Task B showed pictures of a situation and a feeling. People chose a picture of what they could have been thinking.
Step 2: People were split into two groups. Group 1 had a task that asked them to link situations to feelings. Group 2 did not have a task to complete but just watched stories.
Step 3: All people completed Step 1 again: Task A and Task B. We found that Group 1 was better at selecting feelings (Task A) than Group 2 at Step 3. There was little difference between Group 1 and Group 2 when selecting thoughts (Task B).

These results suggest that a computer programme can be used to help some people prepare for therapy.

# Symposium 1.17 Challenging Behaviour, Mental Health Needs and QOL

## An evaluation study of specialized care for people with ID and severe mental health problems

Y. Dijkxhoorn, G.H.A. Wulms & A.C. Louisse

Some people with ID have severe behaviour problems, because of mental illness, bad experiences in the past and/or communication problems. Care providers try a lot of things, ranging from medication, different forms of therapy, activities and so on to help these people, diminish their problems and improve their quality of life. Often their freedom of choice and movement is diminished. To make a minimum of those restrictive measures and a maximum quality of life possible, we try to figure out what works best. We involve people with ID as much as possible, their wants and needs are the most important. Asking their opinion (or that of their family) is also a very important measure of the success of the treatment.

## Reduced incident reports as a measure of improved quality of care

A.C. Louisse, G.H.A. Wulms & Y.M. Dijkxhoorn

## Preventing challenging behaviour of adults with complex needs in supported accommodation

P. McGill, L. Vanono, W. Clover, E. Smyth, K. Henderson, V. Cooper, L. Hopkins & G. Murphy

## A framework to evaluate treatment of clients with intellectual disabilities and severe mental health problems

G. Wulms, Y.M. Dijkxhoorn & A.C. Louisse

# Symposium 1.18 The End of Life and People with IDD

## The Methodology of the Last Days of Life (LDOL) IDRS Study

S. Todd, R. Worth, J. Shearn, J. Bernal, P. Madden, K. Hunt, K. Lowe, E. Jones, P. Jarvis, S. Read, T. Kroll & R. Forrester-Jones

Many people with intellectual disabilities will spend the last days of their lives in a care home and we need more information about what happens to them. We will find this out in three steps:

1: Ask services that provide care homes for people with intellectual disabilities to help us.

2: Send questionnaires to services asking them to tell us when someone who lived in one of their care homes dies.

3: Send another questionnaire to a carer who knew the person who died well. The questionnaire will ask about how the person was looked after at the end of their life.

Many services from across the UK are taking part. The services care for over 10,000 adults with intellectual disabilities. Most of the adults the services care for live in supported living care homes. Not many of the adults are over 70 years old. Asking so many services will help us to get as much information as possible. There are fewer older adults living in the care homes than expected. This means that we don’t know where older people with intellectual disabilities are living at the end of their lives. It is important that we find out this information.

## First Glimpses of the Last Days of Life (LDOL) IDRS Study

S. Todd, J. Shearn, R. Worth, J. Bernal, K.Hunt, P. Madden, E. Jones, K. Lowe, M.McCarron, P. Jarvis, S. Read, T.Kroll & R. Forrester Jones

We need to have information about what is happening to people with intellectual disabilities when they are dying in care homes. We need to find out about as many people as possible from all parts of the UK.

To get this information we will send a questionnaire 3 times to 40 services in the UK who have over 10,000 people with intellectual disabilities living in their homes. We have already asked them to tell us about anyone who had died in one of their homes between July and December 2013. We then asked them to tell us about anyone who had died between January and June 2014. We will send them the questionnaire again to ask about anyone who died between July and December 2014.

We are still being sent information from services but at the conference we will have information about 80 people who died between July and December 2013. We will talk about the age that they died, if they were male or female and where they died.

We need more information to tell us what happens to people with intellectual disabilities when they are dying and the support they might need when they are dying.

## The last months of life of people with ID living in a NZ Service

S. Todd, S. Brandford, G. Bennett & J. Bernal

We need to have information about what happens to people with intellectual disabilities when they are dying. We asked a New Zealand service to tell us about people intellectual disabilities who had died in a group home. They said that 64 people had died in 2 years. We sent the services a questionnaire to find out about the care they got when they were dying. We found that people with intellectual disabilities were dying at a younger age than people without intellectual disabilities. We found that people with intellectual disabilities had been living in a group home for many years but that many did not die there. Instead they were often moved to a large hospital away from the home they knew well. We learnt that many people had not known that they were dying.  We also found that the reason for their death made a difference to how and where they were looked after when they were dying.We think that people with intellectual disabilities need better care when they are dying and more opportunity to die in the place they feel at home in. We need to find out more about how we can support them.

## End of Life Decisions in Adults with Intellectual Disability in Residential Care Facilities in Switzerland

M.T. Wicki, S. Meier & J. Adler

Aim: End-of-life decisions concern difficult medical decisions at the end of the life. Our interest was in finding out how many of end-of-life decisions are made in adults with ID.

Method: A survey was conducted.

Results: People with ID experience a high percentage of end-of-life decisions. Only a third of the people with ID have a do not resuscitate order.

Conclusion: Advanced planning and staff training is needed. This provides a mean to promote self-determination in end-of-life decisions.

## Symposium 2.1 Emotions, Mental Health, Medication and IDD

### Screening for depressive disorders in adolescents with intellectual disability

K.Gray, S. Milsome & G. Melvin

## Reducing the prescription of psychotropics to people with ID

J.H.M.van Loon & P. de Doelder

We know that persons with an intellectual disability get to much antipsychotic medication. Often they get anti-psychotic medication for difficult behavior, while there is not an clear reason for that type of medication.

This study aimed at reducing use of psychotropics among clients of a Dutch service provider. The results of a pilot study among 13 clients will be presented.
The physician looked well into the medical information and did some tests. Also we interviewed the persons regarding their Quality of Life, and we asked the caregivers to report on the persons by daily questionnaires. The effectiveness of the prescribed medication was again considered. Per person action plans were developed to reduce the use of the medication.

With 10 persons we could stop use of a total of 12 medicines. With 4 persons more than one medicine was stopped; 7 people could use less of the medication. We found overall improvement of the functioning, although sometimes we also saw at first increasing challenging behavior.
Interviews with the Personal Outcomes Scale demonstrated a better quality of life. We also saw more alertness, better speech, better sleep and loss of overweight.

Conclusion: In general reduction and a more rational use of psychotropics can be achieved. The challenge is finding other solutions in coping with difficult behavior.

## The assessment of emotional development in persons with ID: Psychometric properties of the Scale for Emotional Development – Revised (SED-R)

S. Vandevelde, F. Morisse, C. Claes, L. Poppe, L. Riské, A. Verduyn, B. Jonckheere & A. Došen

Emotions are important in the life of all people, including people with intellectual disabilities. It is difficult to estimate the emotional development. Therefore, a tool has been developed to help us in measuring emotional development. It is called the “Scale for Emotional Development – Revised (SED-R)".

We need to know if this tool really measures what it pretends to measure. We did two studies to investigate if this tool is a good tool. The first study was done with 67 persons with ID; the second study with 24 persons with ID.

In the first study, we found that the SED-R is a good tool. We are still analyzing the data of the second study. In the presentation, we will discuss some figures of both studies. We will explain why it is important to use the SED-R for the support of persons with ID.

# Symposium 2.2 Mental Health Needs, Challenging Behaviour and Services

## The clinical, forensic, and treatment outcome factors of people with autistism spectrum disorder treated in a forensic intellectual disability setting

V. Chester, F. Esan, V. Chester, I.J. Gunaratna, S. Hoare & R.T. Alexander

## Using privacy preserving data linkage to observe community mental health services delivered to people with an intellectual disability

T. Florio, S. Howlett, H. Xu & J. Trollor

## A survey of in-patient psychiatric care for people with intellectual and developmental disabilities in England

G. Glover, I. Brown & A. Holland

## Changing the way that staff interact with people who have challenging behaviour: a review

J. Webb, J. Clegg & A. Pilnick

## Symposium 2.3 Rett Syndrome – 1

### Lost in Transition – Quality of life and transitional process to adult health services in patients with Rett syndrome

M. Freilinger, L. Schoberth, R. Jagsch & A. Novak

Rett syndrome is a rare neurological disorder affecting girls. It was first described in Vienna by Andreas Rett in 1966. Over the years the life span of these women with severe disabilities has increased. We want to know about quality of life in this patient group gather informations about the transition to adult medical and social health care services. Parents of 43 patients with Rett syndrome aged from early childhood to adulthood were asked. We present and want to discuss the key aspects of quality of life and transition process. Our findings and experiences can help to implement or improve transition processes also in other patient groups with intellectual disabilities.

## En route to disentangle early behavioral abnormalities as early markers for maldevelopment: learning from Rett syndrome

P.B. Marschik, K.D. Bartl-Pokorny, F. Pokorny & C. Einspieler

## Rett syndrome and older age

E.E.J. Smeets, P. Thiry, N.S.J. Halbach, D.A. van Waardenburg & L.M.G. Curfs

## Growth faltering and osteoporosis in Rett syndrome

D.A. van Waardenburg, E.E.J. Smeets, N.S.J. Halbach & L.M.G. Curfs

# Symposium 2.4 Mortality and IDD

## Possibilities for monitoring mortality data in different parts of the UK

G. Glover

## Is a paper-based review of deaths sufficient?

P. Heslop, A. Marriott & M. Hoghton

In England, a Confidential Inquiry into premature deaths of people with intellectual disabilities (ID) was held. It decided to talk to people about what had happened to people who had died. This presentation explains why. The CI looked into the deaths of 247 people with ID in England. Some nurses and people called investigators talked to everyone who had been supporting the person who died. The nurses or investigators talked to about seven different people about any one person who had died. They talked to the doctors and nurses treating the person, their carers and their family and friends. We found that no-one knew everything about the person who had died. Lots of people had a little bit of information each. Families often knew the most about what had happened to the person. Sometimes different people said very different things about what had happened. Some people preferred talking to the nurse and investigator. They didn’t want to write things down. It is important not to rely on a person’s records. To find out what really happened to a person we need to talk to those who knew them best.

## Coding on cause of death certificates – issues for people with intellectual disability from the US and England

E. Lauer, P. Heslop

Aim:
Looking at information about births and deaths can help us learn more about the health of large groups of people. In both the United States and the United Kingdom, the reason a person died is listed on their death certificate by a doctor.

We looked at how doctors describe the cause of death in each country. This will help us understand whether the reasons people with disabilities die are different between each country, or whether the reasons for death are just described differently.

Methods: Compare information about deaths of people with intellectual/learning disabilities across the two countries. We looked at both death certificates and other information about the person's health.

Results: There are important differences in how the cause of death is described between the two countries, both for people with and without disabilities.

Conclusions: There may be differences in how the cause of death recorded because there are differences between the two countries in how doctor's assess people's health, or how often the causes of death are investigated.

It is important to think about which differences may be due to how the information is recorded, and real differences in the reasons people with disabilities die between the two countries.

# Examining mortality among adults with intellectual disabilities in Ontario, Canada

H. Ouellette-Kuntz & R. Balogh

## Symposium 2.5 Health and PIMD

### Safety and danger awareness in people with profound intellectual and multiple disabilities: exploratory study based on some caregivers' points of view

G. Petitpierre & J. Gyger

### Re-labelling behaviour: the effects of psychoeducation on identifying challenging behaviour in people with profound intellectual and multiple disabilities

P. Poppes, A.A.J. van der Putten & C. Vlaskamp

### Unsafe soundscapes as a cause of challenging behavior in people with profound intellectual and visual disabilities

K. van den Bosch, T. Andringa & C. Vlaskamp

# Symposium 2.6 Mindfulness, Mentalising and Prejudice in IDD

## Case studies on mentalizing and non-mentalizing communication during daily care for children and adults with a visual impairment, intellectual disability and/or with problematic attachment

F. Dekker & P.S. Sterkenburg

## The effects of mindfulness for people with visual impairment and moderate intellectual disability and their caregivers

H. Hokke, P. Lievense & P.S. Sterkenburg

## The effect of a recently developed serious game on prejudice towards persons with disabilities

P.S. Sterkenburg & F. Juriëns

# Symposium 2.7 Health and Families of People with IDD

## The impact of educational involvement on psychological adjustment among mothers of children with autism spectrum disorder: a longitudinal study

P.R. Benson

## Physical and mental health of families co-residing with an adult with an intellectual disability

J. Grey,V. Totsika & R. Hastings

## The impact of challenging behaviour on parental and child wellbeing

E. Karakatsani,D. Adams, C. Oliver & N. Jackson

## What can health models tell us about parental perceptions of challenging behaviour?

J. Waite,C. Oliver, J. Moss, K. Eden & L. Wilde

# Symposium 2.8 Rett Syndrome – 2

## A systematic review of the Rett Syndrome behavioural phenotype

R. Ciangalione, M. Kerr, D. Felce & R. Hastings

People with Rett syndrome usually have a number of similar difficulties. They do little with their hands other than simple repetitive movements. They have little speech, may have problems walking and sometimes breathe too little or too much.

We wanted to find the evidence for thinking that people with Rett syndrome behaved similarly to each other. We looked for all of the research we could find that described the behaviour of people with Rett syndrome.

We found 4 studies that described their behaviour generally, 14 that investigated particular behaviours, 18 that compared their behaviour to that of other groups of people, and 11 that looked at whether there was an association between their behaviour and the precise genetic cause of their Rett syndrome. This evidence will be described.

Overall, we found that repetitive hand movements, abnormal breathing and sleep problems are typical but some other behaviours, such as self-injury, are not.

## Self-injury in Rett Syndrome

D. Felce, R. Cianfaglione, M. Kerr & R. Hastings

Several surveys have found that about a half to three-quarters of people with Rett syndrome injure themselves. We wanted to find out more about self-injury among people with Rett syndrome.

We asked the parents of 91 girls or women with Rett syndrome to answer questions about their daughters' self-injury. We also compared their answers to those for another group of people of the same sex, age and skill level whose disabilities had another cause. And we observed some of the people with Rett syndrome during the day to see how much and when they injured themselves.

In our sample, self-injury was reported in just over a quarter. This was less than in the comparison group. People with Rett syndrome who injured themselves were more severely disabled and were more overactive and impulsive than those who did not. From the observations, we found that people injured themselves less when they received attention from someone else. Their self-injury might be a way of getting attention.

We think that self-injury is not typical of people with Rett syndrome and probably happens for the same reasons as it does for some other people who also injure themselves.

# The psychological well-being and adjustment of families with a daughter with Rett syndrome

R. Hastings, R. Cianfaglione, M. Kerr & D. Felce

Children with severe disabilities often have parents who feel more stressed, anxious and depressed than other parents. We wanted to find out whether this was also true of parents of children with Rett syndrome.

We asked the parents of 80 girls or women with Rett syndrome to answer questions about how they felt. We asked half of them the same questions again 16 months later.

We found that parents’ stress, anxiety and depression were related to the level of their daughter’s behavioural problems not to the severity of their condition. Parents reported little change over time, although their stress had increased second time around. Stress, anxiety and depression were linked to parents thinking that their daughters were getting worse. Parents feeling positive was linked to them feeling that their daughters were improving.

Overall, we found that parents felt worse if their daughter had greater behaviour problems or if they thought that their daughters were getting worse.

## Ageing in Rett Syndrome

M. Kerr, R. Cinafaglione, D. Felce & R. Hastings

We wanted to find out how people with Rett syndrome change as they grow older.

We asked the parents of 91 girls or women with Rett syndrome to answer questions about their daughters’ health, what they could and could not do, and the problems they had. We asked them the same questions again 16 months later.

We found that severity of disability, health and behaviour problems typical of Rett syndrome did not differ across age groups. Older people had slightly better skills in some areas. Younger children were more overactive and impulsive but had more positive mood than adults. When we asked again, skills and behaviour were similar to before. But health had got worse and people’s mood was less positive.

The impression that people with Rett syndrome do not change a lot as they grow older was confirmed but some effects of ageing were detected.

# Symposium 2.9 Epilepsy and Foetal Alcohol Spectrum Disorder

## Exploring the medical and social needs of people with intellectual disability who have epilepsy.

M. Kerr

We need to have information about what life is like for people who have both an intellectual disability and epilepsy and how life can be improved. For example, we need information about:
How do people with intellectual disabilities get diagnosed with epilepsy?
What treatments (drugs, surgery) are available for people with epilepsy?
How good is the support from medical staff and support staff?
Do people who have an intellectual disability and epilepsy have the same chance to have (a) a job (b) education (c) friends as everybody else?

We came up with an online survey (on the internet) to answer these questions. 133 people answered the questions, from 13 different countries.
People working in health, support staff and family answered the questions.

They told us:
Medical staff need special training to help people with both intellectual disabilities and epilepsy.
We need more staff with this training.
Medical staff did not always respect and listen to people.
Discrimination (not being treated the same as everyone else) stopped people having choices and a good life.

At the end of our presentation we will talk about how services can be changed to provide better support for people with intellectual disabilities and epilepsy.

# Children at risk of prenatal alcohol damage perform below average compared to their non prenatal alcohol exposed peers on a neurodevelopmental test battery

S. Roozen, A. Toornstra, G.J. Kok & L.M.G. Curfs

# Does an Intellectual Disability (ID) Epilepsy service improve outcomes for patients with ID and epilepsy? A 9 year study of Sudden Unexpected Death in Epilepsy (SUDEP) in the UK

R. Shankar, D. Cox, B. McLean, J. Hanna, C. Jory, M. Tripp & M. Walker

People with ID are more likely to have epilepsy and there are more deaths due to epilepsy in people with ID as opposed to general population. In Cornwall UK there is a specialist service for people with ID and epilepsy.

We looked to see if this service was helpful in reducing deaths. We examined the records at the Coroner of all the deaths of epilepsy in Cornwall between 2004 and 2012.

We found that Cornwall had much less deaths in people with ID and epilepsy than regional or national average and when compared to other places.

The speech is on presenting what we found and what we think we do differently which helps possibly protect lives.

# Fetal alcohol syndrome disorder in a rural area of the South West Ukraine

A. Toornstra S. Roozen, G.J. Kok & L.M.G. Curfs

# Symposium 2.10 Mental Health and Mental Well-Being

## Self-reported mental well-being in adolescents with intellectual and developmental disabilities: an initial psychometric evaluation of the WellSEQ

J. Åsberg Johnels, P. Boström & M. Broberg

## Development of a self-report mental health questionnaire (WellSEQ) for adolescents with intellectual and developmental disabilities

P. Boström, J. Åsberg & M. Broberg

## The Mental Health of 11 Year Old Children with and without Intellectual and Developmental Disabilities

E. Emerson, C. Hatton, J. Robertson, S. Baines, V. Totsika & R.P. Hastings

Some children with intellectual disabilities are unhappy. We want to know why.

We are looking at children in the UK from a very early age until they are 11.

We are still working on this project.

We will tell you what we found at the conference.

## Psychometric properties of the Strengths and Difficulties Questionnaire (SDQ) among school aged children with developmental disorders and intellectual disabilities

M. Halvorsen, B. Mathiassen, E. Myrbakk, P.H. Brøndbo, J. Sundby, O. Steinsvik & M. Martinussen

We need to have information about the mental health and well-being of children and adolescents with intellectual disabilities
The Strengths and Difficulties Questionnaire is a survey of mental health that is often used among children in general.

We wanted to find out if we could use this survey among children and adolescents with developmental disorders and intellectual disabilities.

The speech will be about this survey and our experiences with using the survey among children and adolescents in Norway with developmental disorders and intellectual disabilities.

# Symposium 2.11 Injuries, Safety and Accidents in IDD

## Dysphagia-related safety for adults with developmental disabilities: restrictions, risk and complacency

B. Hemsley, S. Balandin & J.J. Sheppard

## Two-year incidence of injuries amongst adults with intellectual disabilities who live with paid support in Scotland, UK.

E. Petropoulou, J. Finlayson & D.A. Skelton

Aims:
Adults with intellectual disabilities have more injuries than people without intellectual disabilities. We want people with intellectual disabilities to have fewer injuries and to be healthier. To do this, we need to have information about how many times they have an injury and why. This will help us reduce or prevent injuries.

Method: We worked with three organizations in Scotland who support adults with intellectual disabilities, who live with paid support. These organizations use an electronic system, where they write down the details of each injury when it happens and gives it to us anonymously. We used the reports from the 2 previous years (2012 & 2013) to find out information about these injuries. Results: Meantime, we found from the reports from two of the three organizations that there were 2,775 injuries among 356 adults with intellectual disabilities the last two years (2012-2013). Most of the injuries were caused by falls.

Conclusion: By knowing more about when, where, and why an injury happens, we can help people prevent them. Working closely with supporters will allow us to develop standard procedures that could be easily applied anywhere and help people around the world.

## An approach to minimizing restrictive practices resulting in sustainable organizational gains and individual outcomes

J.S. Zeiter & L.A. Marshall

## Systemic Therapy for adult Persons with intellectual Disability and psychiatric Disorders: A Pilotstudy on Prevention of physical Aggression, Restraints and Staff Burnout in a Cross-Institutional setting

F. Gaese, E. Nicolai, E. Nagy & J. Schweitzer-Rothers

During a two-years training time we want to find out more about if we can use family therapy methods to prevent violence burnout of staff. And we want to find out on what we have to pay attention if we want to have success. Fore that we want to better figure out, what helps to solve conflicts in the living environment in a home and what helps to avoid anger and violence. And how we can work more mindful together. By collecting data every three months we will follow the process and see how it developes. We count aggressions and restraints and hope they will fade. And we ask the staff to answer many questions. For example about their age, their well-beeing in work, if they experience themselves helpful. After the two years we will look if the good results can be kept.

## Secure inpatient services for people with intellectual disability: do we need them?

I. Hall, E. Yacoub, M. Beadman, S. Holder, R. Stamps, R. Bates & N. Boast

## Complex behaviour service: enhanced model for challenging behaviour

A. Hassiotis, S. Inchley-Mort, C. Wahlich & K. Rantell

## **Exclusive** treatment or inclusive **expertise?**

P. van Belle-Kusse

## Symposium 2.13 Ageing and IDD

### Supporting Older Adults with ID to engage in Health Screening: Lessons learned from The Irish Longitudinal Study on Ageing (IDS-TILDA)

E.A. Burke, P. McCallion, J.B. Walsh & M. McCarron

Going to the doctor and getting health checks regularly is very important to keep us all well. This study was to find out what made it easy for people and what made it hard for people when going for health checks. First we asked people with ID and professionals to give us advice on what health checks to do and how to explain the health check so people with ID would understand them. In the study the researchers set up a health fair which was made up of 7 different health checks like measuring people's height or measuring blood pressure. Most people with ID agreed to do the assessments and some chose not to. The results of this study told us that sometimes health checks need to be made to suit the person and this will make sure they are able to get regular health checks.

## Comparing hearing and sight loss among the older general population and among older people with an intellectual disability living in Ireland.

E. Cleary, M. McCarron & P. McCallion

Many people have problems with hearing and eyesight as they get older and sometimes these occur together. We want to know how many older people with an intellectual disability in Ireland have both eyesight and hearing problems. We also want to know how many people from the general population have the same problems and compare numbers from both groups.

We spoke to people with intellectual disabilities and their carers and asked them to tell us how good they think their hearing and eyesight is. They gave one of six answers.

Excellent

Very good

Good

Fair

Poor

Legally blind or legally deaf

We found that twenty seven percent of people with an intellectual disability had a hearing or eyesight problem compared to twenty three percent of people from the general population.

Five and a half percent of people with an intellectual disability had both hearing and eyesight problems while only just over three percent of people from the general population had both hearing and eyesight problems.

# Utility of a frailty index in older adults with an intellectual disability: preliminary findings from intellectual disability supplement to the Irish longitudinal study on ageing (IDS-TILDA)

M. McCarron, R. Carroll, E. McGlinchey, E. Cleary & P. McCallion

# Symposium 2.14 Health Services and People with IDD

## Treatment of people with intellectual disability in the NHS: a report from England

A. McClimens, J. Brewster & R. Lewis

## The barriers to providing reasonably adjusted health services to people with intellectual disabilities in acute hospitals: evidence from a multi-methods study

I. Tuffrey-Wijne

## A new model for understanding effective carer involvement for people with intellectual disabilities in acute hospitals

I. Tuffrey-Wijne

## ‘Invisible patients’: the barriers to identifying people with intellectual disabilities in acute hospitals in England

I. Tuffrey-Wijne

# Symposium 2.15 Health, Health Services and People with IDD

## Behaviour and emotional problems in children with developmental disabilities: results of an Australian population level survey

K. Gray, B. Tonge, J. Taffe, S. Einfeld, M. Sanders & K. Sofronoff

## Hospital staff experiences of caring for children and youth with ID and their families: it's the little things that make the difference!

K.Oulton, S. Kerry, L. May, D. Sell, C. DeSousa & F. Gibson

## The convention on the rights of persons with disabilities and its implications for the health and wellbeing of indigenous peoples with intellectual disabilities

M. Rivas-Velarde

## Unforeseen' Health Issues as People with Disability Age: A Wake-up Call in Rural and Regional Areas

K. A. Willsher

Many people who are born with disability now become adults.
There has been very little research on the health problems that people born with disability in country areas suffer from.
There needs to be more knowledge so that health services can be improved in country areas.

How the Research was carried out:
The speaker interviewed fourteen rural parents who had brought up a child that had been born with a disability. The speaker also asked about difficulties the parents had in obtaining health care for their child as they moved into adulthood. The speech will be about this research.

What the results were:
The speaker found that parents are concerned about the future, obtaining services and what happens when their child needs to move to adult services. Nine children who had not been expected to live to adulthood had developed heart disease or dementia at a young age.

The speaker found out from the parents that they would like more health services near where they live. They also wanted to be involved in the decision making.

## Symposium 2.16 Health, Sleep and Obesity in People with IDD

### Comparison of sleep parameters and associated factors in a matched nationally representative population sample in persons with and without an intellectual disability.

N. Mulryan, E. Cleary, R. Carroll, B. Lawlor, P. McCallion & M. McCarron

We wanted to see what was the same or different about sleep in people that had an intellectual disability and those without an intellectual disability. All the people that told us about their sleep were 50 years of age or older and lived in Ireland. Every person that had an intellectual disability was compared to someone that didn't have an intellectual disability and was the same age, lived in the same type of area and was a man or woman like them. Both groups of people told us they had a lot of sleep problems. The people that had an intellectual disability had more sleep problems than the other group. The things that made people sleep badly were almost the same in both groups.I will talk about the things that were the same or different about sleep for both groups.

### Special needs for health care of people with intellectual or multiple disabilities

J. Nicklas-Faust

## Psychological treatment for sleep problems in adults with intellectual disabilities.

P. Triantafyllopoulou, P. McGill, P. Chiu & G. Murphy

Sleep is very important for our health. People with ID are known to have more sleep problems than other people. This study wanted to see if psychological sleep treatment can help adults with ID.

64 adults with ID and their carers agreed to take part in the study. Half had treatment and half were the comparison group. We checked everyone's sleep, their behavior and how well they could do things on their own. The treatment included 4 group sessions where psychological treatments for sleep problems were taught.

The results of the study didn't show any differences between the two groups (treatment and control group). But all participants had a sleep improvement. We also found that people with more disabilities had more sleep problems. Also, people who showed more challenging behavior also had more sleep problems. The information we collected from the staff members showed that most of the staff didn't carry out the treatment.

It was concluded that future research should re-examine how to deliver training material to staff and to include some hands- on training.

## Obesity and hypertension in adolescents and adults with intellectual disability

H. Yıldırım Sarı, M. Yilmaz, E. Serin, S. Secgin Kısa, Ö. Yesiltepe, Y. Tokem & H. Rowley

# Symposium 3.1 Health and Specific Syndromes

## Amino acids and cognitive deterioration in 22q11 deletion syndrome

L. Evers, T. van Amelsvoort, J. Bakker & L. Curfs

## Health and social care resource use by individuals with fragile X in Canada and the UK

A. Hassiotis, P. London, T. Bostock, K. Lakhdari, N. Adlard, G. Aubertin, P. Burge,

F. Corbin, S. Gagnon & S. Barry

## Twenty-four hour-response curve of melatonin in Smith- Magenis syndrome

K. Spruyt, W. Braam, M.G. Smits & L.M.G. Curfs

## Caregiver reported sleep onset latency, night-waking and early waking in Smith-Magenis Syndrome

K. Spruyt, W. Braam, M.G. Smits & L.M.G. Curfs

# Symposium 3.2 Health Care and Health Checks

## Effectiveness of annual health checks for patients with intellectual disability in primary care

A. Hassiotis, M. Buszewicz, C. Welch, L. Horsfall, I. Nazareth, D. Osborn, G. Glover, U. Chauhan, M. Hoghton, A. Cooper, G. Moulster, R. Hithersay, R. Hunter, K. Courtenay, P. Heslop & A. Strydom

## Comprehensive health assessments for adults with intellectual disability (ID) in Manitoba: a feasibility study

S. Shooshtari & B. Temple

## Access to primary health care and problems managed for people with an intellectual disability: lessons from the BEACH dataset

J.N. Trollor, J. Weise, A. Pollack & H. Britt

## The evaluation of inequality in health care utilization for people intellectual disabilities in Taiwan

Y.-J. Wang & K. Wang

# Symposium 3.3 Training in IDD for Professionals

## Evaluation of the World Health Organization mental health gap programme on people with disorders of intellectual development: the Sri Lanka experience

S.E. Cooray, S. Bhaumik, R. Gumber, S. Gangawati, J. Mendis & C. Abeywickrema

## The views and experiences of family carers and students who participate in a Family Placement Scheme as part of experiential learning in intellectual disability nursing education in Scotland, UK

J. Finlayson & C. Darbyshire

Aims: Family placements mean students in intellectual disabilities nursing can spend time working with families. Families who care for someone who has intellectual disabilities at home. Family Placements help students learn more about this. They help family carers be more involved in educating students about their needs. Our university in Scotland has a Family Placement Scheme for students. However, we do not know enough about the opinions and experiences of the carers and students who take part in it.

Method: We are inviting 90 students and 18 carers to fill in a questionnaire about their opinions and experiences of the Scheme. We are also inviting the carers to take part in research interviews. The interviews will tell us more about their opinions and experiences.

Results: Thirty students and 5 carers have told us about their experiences so far. We will be telling you what they have told us during this presentation.

Conclusion: Carers' and students' opinions and experiences are very important for letting us know what it good about the Family Placement Scheme, and what we can do to make it better. Involving family carers in intellectual disabilities nurse education is very important.

## Involving people with intellectual disability in the assessment of clinical skills

I. Hall, S. Soni, P. Doulton & P. Bowie

## An exploration of the Irish intellectual disability nursing profession’s opinions as to the potential future shape of professional curricula in 21st century Ireland

P. Horan, C. Griffiths, C. Crofton, P. Keenan, S. Fleming & F. Sheerin

## Symposium 3.4 Health, Health Surveys and People with IDD

### Suicidality in people with intellectual disabilities: a systematic review

P. Dodd, S. Guerin & A. Doherty

### Demographic and health status profiles of young adults with ID in Canada

B. Isaacs, J. Weiss, E. Lin & Y. Lunsky

## IDS-TILDA Wave II: First report of mental health variables

N. Mulryan, E. Cleary, R. Carroll, B. Lawlor, P. McCallion & M. McCarron

We wanted to know how sad or worried people with an intellectual disability can feel.

Almost 700 people with an intellectual disability living in Ireland told us about how sad or worried they can feel. We also asked them if anything important had happened in their lives and many other questions. All the people that answered the questions were 40 years of age or older. When we finished asking the questions we looked at all the answers and wanted to show if there was a connection between some of the answers. We also looked at what they answered 2 years ago when we asked them questions like this.

We showed that many people felt sad and worried at times. Many of these people took tablets or got other types of help to make them feel better. The answers were very like the answers they gave to the questions 2 years ago.

We also found out that people with an intellectual disability feel sad or worried more than people that do not have an intellectual disability.

## Surveillance study of the Japanese child developmental support center for children below school age

K. Yamane& the Council of Child Developmental Support in Japan

Survey of the Japanese child developmental support center below school age. In Japan the Child Welfare Act was revised in 2012. After which a lot of child developmental support facilities were unified. But the medical type of child developmental support facilities were not unified. (hereafter referred to as MCDS).

We collected information about 1,554 facilities and 52,221 children. For example:
Present support,
Disease of children,
Medical care of children, etc.

Results:  There are a lot of children who need medical care at MCDS. Epilepsy was the most common. Utilization was low at MCDS. The personnel standard of direct treatment staff was 4:1 and the survey average was 2.67:1.

MCDS have no personnel standard, and the survey results varied. Future improvement require:
Human resource development,
Better accessibility,
Financial and management base stability.

We suggest solutions, like financial support, a personnel standard of 3:1 at all facilities, better training, etc.

## Symposium 3.5 Trauma, Attachment and Psychotherapy

### Psychotherapy in people with intellectual and developmental disabilities

S. Elstner

### Attachment disordered behavior and other forms of psychopathology

H. Giltaij, P.S. Sterkenburg & C. Schuengel

### Safe to succeed: importance of creating a trauma-informed environment to promote self-determination

L. Marshall & J.S. Zeiter

# Symposium 3.6 Medication Use and People with IDD

## Medication use among adults with intellectual and developmental disabilities

V. Cobigo, H. Ouellette-Kuntz, J.K. Lake, A.S. Wilton & Y. Lunsky

We counted the number of medications (all types such as pills, syrups, etc.) adults with intellectual and developmental disabilities (IDD) take. We also looked at who is taking more medications. For example, are women with IDD taking more medications than men? We looked at the medications taken by 52,404 adults with IDD living in Ontario, Canada on October, 2009. We know about the medications they take because the government pays for the medications taken by persons with disability. We counted all medications they were using on October 1, 2009. Three in 5 adults with IDD were taking at least one medication, and many of them were taking more than one medication at the same time. Women were more likely than men to be taking more medications at the same time. It is sometimes dangerous to take many medications. It is important to support persons with IDD to use medication safely.

## Presence and determinants of physical health parameters in people with intellectual disability who use long-term antipsychotics

G. de Kuijper, H. Mulder, F. Visser, H. Evenhuis & P.J. Hoekstra

## Quality Indicators of the Medication Use Process in Adults with Intellectual Disabilities and Behaviour Disorders: An opportunity to address health inequities.

B.Flood & M. Henman

People with intellectual disabilities and behaviour problems have different health than other people. This is unjust. This can be prevented. People with intellectual disabilities and behaviour problems use a lot of medicines. Many people are concerned about the use of these medicines.

We need ways to find out the quality of medicine use. This project was a Delphi study. The researcher read the journals and found ways to look at quality. The researcher sent the information she found to 28 experts. These were psychiatrists, pharmacists, psychologists, nurses, speech and language therapists and others. These experts agreed with the information the researcher found. The experts gave the researcher information she used to make high, medium and low level quality indicators. Quality indicators are like signposts for quality. These indicators will let people measure the quality of medicines use. This may improve health outcomes for people with intellectual disabilities and behaviour problems.

## People with intellectual disabilities and the medication use process. Grounded Theory analysis of information from interviews with 6 people

B.Flood & M. Henman

Many people with intellectual disabilities takes medication.

In this project a pharmacist interviewed six people with intellectual disabilities. The people answered questions and gave information.

This project showed that people with intellectual disabilities

1. Are able to give information about medicines
2. May know why they are taking medicines and the name of the medicine
3. May not understand 'side effects'
4. May understand 'good' and 'bad' things about medicines
5. Depend on others to bring them to the doctor and the pharmacist
6. May like more 'privacy' about using medicines
7. May feel that others make decisions about medicines for them
8. May find diabetes distressing
9. May have few problems managing diabetes.

# Symposium 3.7 Cognitive Stuimulation, Health and Dementia

## Efficacy of a cognitive stimulation therapy programme with adults with Down syndrome: a randomised study

S.Collins & S. Shanahan

All older people can become forgetful and people with Down Syndrome experience this too. Groups have been run using enjoyable games and activities that have helped older people's memory, thinking and enjoyment of life but no one had tried this with people with Down Syndrome.

This study took place in Southern Ireland.The people who had taken part in the group seemed to have improved on their ability to know where they were and on how they felt about the quality of their lives. Everyone enjoyed taking part in the groups.

Unfortunately after three months there was not any difference between those who had taken part in the group and those who did not.

This looked like an interesting thing to have done but probably needs to be done again with a lot more people and for a lot longer time.

# The effectiveness of life story books and rummage boxes on the well-being of individuals with Down syndrome and dementia: a randomised single case series experiment

N. Crook & P.Langdon

AIMS: We tried to find out whether life story books and personalised rummage boxes helped people with Down syndrome (DS) who have dementia to feel better.

METHOD: Five people used the life story books and rummage boxes.

RESULTS: The findings showed that three people seemed to feel better when they used the life story books and rummage boxes, but some people liked the life story books or rummage boxes better.

CONCLUSIONS: The findings suggest that these things could be helpful for people with DS and dementia.

## Support to co-residents of people with dementia and intellectual disability in group homes

B. Lindmeier

## Antidepressants increased longevity and delayed onset of dementia in adults with Down syndrome

J. Tsiouris, P. Patti & M. Flory

## Symposium 3.9 Health, Sexuality and Screening

### Exploring opportunities for sexual health screening for women with intellectual disability in Malta

C. Azzopardi Lane

Women with intellectual disability have less opportunities to check their sexual health when compared with women who do not have a disability. These check ups are important to find out if there is something wrong like a cancerous growth in the women's reproductive and sexual body parts. I asked:
Do they know that they need these check ups?
Do their families and people who provide a service to them understand how important these check ups are?
I asked 10 women with intellectual disability, 3 parents and 3 service providers, a list of questions about sexual health check ups.

I found that very few people of those that answered the questions knew about sexual health check ups, therefore women with intellectual disability didn't do them.

More needs to be done so that women with intellectual disability have the opportunity to do these check ups.

## Breast Cancer and Women with Intellectual Disability : Are We Screening?

C. Azzopardi Lane

Cancer screening is unnecessary for these women. All women can develop breast cancer. It is important for all women to have their breasts checked regularly by a doctor.
People think that it is not necessary for women with intellectual disability to get their breasts checked.
I asked: Do women with intellectual disability know that they need to check their breasts for lumps?
Are the families and the people who work with women with intellectual disability informed about breast cancer?
Do women with intellectual disability, their families and people who work with them know about the available breast cancer check-ups?

I asked 10 women with intellectual disability, 3 parents and 3 service providers, a list of questions about breast cancer in women and how to check for it.

I found that many people knew about breast cancer but very few knew about or carried out check ups. Women with intellectual disability need to have the opportunity to do these check ups as other non-disabled women do.

## Constructing Sexual Identities: People with Intellectual Disability Talking about Sexuality

C. Azzopardi Lane & A.M. Callus

Young people with intellectual disability are encouraged to speak-up for themselves. This is also known as self-advocacy. A group of young people with intellectual disability wanted to speak about sexuality, relationships and disability. The research was carried out in Malta. The people with intellectual disability were co-researchers and that made their own presentation.
The group spoke about:
How they feel about their sexuality
What they would like to learn more about
Who helps or hinders their opportunities to have a relationship and express their sexuality and how.

We found that people with intellectual disability who took part in the research are aware of their sexuality and interested in exploring the subject further.

They also told us how important their parents are in their lives and how they can control their opportunity to have relationships.

## Working with adults with intellectual disabilities to promote their sexual health: Program innovation, implementation, and evaluation

Y.-C. Chou, Z.-Y. Lu, C.-J. Lin, C.-Z. Shi & H.-F. Chou

Just like for all people, sexual health is important and a human right issue for people with intellectual disabilities. In 2013, we invited two adults with intellectual disabilities (one man and one woman) to be members of our research team to develop, implement and evaluate an intervention.

The goal of our intervention was to promote knowledge on sexual health and quality of life for adults with intellectual disabilities who participated in this intervention.

We studied whether the intervention increased sexual knowledge among those adults who participated in it, making a survey before and one week after the intervention.

The results showed that the intervention made a difference, increasing knowledge and positive attitude towards sexuality. However, six months after the intervention, there was no difference in the level of knowledge on sexual health between those adults who participated and those who did not participate in the intervention.

The two adults who were members of our research team told that they felt happy and empowered in sexual rights as a result of their involvement in this project.

# Syamposium 3.10 Parents with IDD

## Reviewing intervention plans and collaboration between specialized and child welfare agencies in the lives of parents with intellectual disabilities

M. Aunos, L. Pacheco, G. Goupil & N. Poirrier

## The social and emotional wellbeing of young children with mothers with and without cognitive limitations

G. Hindmarsh, G. Llewellyn & E. Emerson

Aims: We looked at the social and emotional health of two groups.Children with mothers with cognitive limitationsChildren with mothers with no cognitive limitations

Method: The information was collected when the children were 9months, 3, 5, and 7 years old. Information about health, the household, the neighbourhood, and money were asked. The child's social and emotional health was measured at 3, 5, and 7 years.

Results: Children with mothers with cognitive limitations are living in poorer environments. We also found some differences in their social and emotional health.

Conclusion: This study tells us about social and emotional health of children with mothers with and without cognitive limitations.

# Using longitudinal data to examine pregnancy outcomes among women with and without intellectual and developmental disabilities

M. Mitra, S.L. Parish, X. Cui & H. Diop

We need to know more information about women with intellectual disabilities who give birth. Are they healthy? Are their newborn infants healthy? Do they get the health care they need from doctors and nurses when they are pregnant? We looked at information from birth certificates and hospitals in Massachusetts, USA to learn about these women's health care. There were about 485 women with intellectual disabilities in the survey who gave birth between 1998 and 2009. We learned pregnant women with intellectual disabilities often have newborn babies who are small and born too early. The women with intellectual disabilities often get high blood pressure and other illnesses during pregnancy. The pregnant women also do not get help from doctors and nurses as much as they should. Women with intellectual disabilities also tended to be very poor and not identify their baby's father at birth. This means that new mothers with intellectual disabilities may not get the support they need to take care of their newborn babies.

# A national profile of deliveries by women with intellectual disabilities in the US: Maternal characteristics and pregnancy outcomes

S.L. Parish, M. Mitra, E. Son, A. Bonardi & P. Swoboda

We need to know if women with intellectual disabilities and their newborn babies get the health care they need from doctors and nurses. And it’s important to understand if these women and their newborn babies are healthy. We looked at information from hospitals in the USA to learn about these women’s health care. There were about 340 women with intellectual disabilities in the survey who gave birth in 2010. We learned that pregnant women with intellectual disabilities often have newborn babies who are small and born too early. The women with intellectual disabilities often get high blood pressure and other illnesses during pregnancy. We learned that pregnant women with intellectual disabilities and their newborn babies need better care from doctors and nurses. They also may need to learn how to take care of themselves when they are pregnant.

# Symposium 3.11 Parents of Children with IDD

## The life stories of families with children with intellectual disability: what issues do they face in Croatia?

N. Lisak & D.Bratković

## Factors associated with the psychological wellbeing among parents of young children with developmental disabilities attending early intervention programs in Singapore

K. Poon, N. Ooi & R. Bull

## Hope, optimism and resilience in a group of parents of children with disability

S. Santilli

## Becoming the parent of a child with a disability: psychoanalysis and politics

B. Watermeyer

# Symposium 3.12 Health in Down Syndrome and End of Life Issues

## Evaluation of fine movements in persons with Down syndrome

G. Albertini, M. Galli & C. Condoluci

## Study of cardiac risk parameters in adults with Down syndrome

C. Condoluci, M. Galli, V. Cimolin, C. Rigoldi & G. Albertini

## The preservation of dignity at end-of-life

E. Reilly, P. Dunne, S. Nelson & M. McCarron

## Identifying good practice in relation to palliative care for people with intellectual disabilities: examples from 14 European countries

I. Tuffrey-Wijne, B. Maes, M. Murko, L. Igric, A. Wagemans, L. Curfs, E. Fahey-McCarthy, E. Flygare Wallen, M. Wicki, A. Dusart, L. McEnhill, D. McLaughlin, D. Oliver, S. Read, K. Ryan, D. Satgé, B. Straßer, B. Westergaard & C. Hoenger

## Symposium 3.13 Ageing and IDD

### Developing a Baseline Picture of the Bone Health Status of Older Adults with an Intellectual Disability in Ireland.

E.A. Burke, P. McCallion, J.B. Walsh & M. McCarron

This study is about how healthy people's bones are. This is very important because if your bones are not healthy they can break easily. The results come from a study called IDS-TILDA.

We asked people to tell us if the doctor had ever told them they had any health conditions. We asked them what health services they used. We asked them what their diet was like and what tablets or medicines they took. We also asked them how much exercise they did.

We found out that very few people had poor bone health even though they did not exercise a lot or eat a well-balanced diet. But a lot of people told us they did not get the test done to measure how healthy their bones were.

This study tells us that people with ID might have a lot of poor bone health that we don't know about. This should be examined further.

## The German ageing and disability study: setup and baseline results

K. Hoffmann

## Prevalence and Factors associated with High Anticholinergic Burden in Ageing People with Intellectual Disabilities in Ireland

M. O’Dwyer, J. Peklar, I. Maidment, M. McCarron, P. McCallion & M. Henman

“Anticholinergic medicines" are often used by older people and may have side effects such as drowsiness and constipation. As people with intellectual disabilities get older, they are likely to use anticholinergic medicines to treat health conditions they have, such as mental health disease. We wanted to find out how many anticholinergic medicines and what types of anticholinergic medicines older people with intellectual disabilities used.

There is a large study called IDS-TILDA in Ireland that has 753 people with intellectual disability over the age of 40. We looked at what medicines they were taking. We used a scale to understand how many anticholinergic drugs people were taking. We found that most people were taking drugs that had anticholinergic effects, and many people reported drugs that had large anticholinergic effects. Many people reported taking more than one anticholinergic medicine.

We found that there was a link between people who had a lot of health conditions, who were older or who were living in a residential setting and use of medicines with large anticholinergic effects. Use of anticholinergic medicines was high in our study. Older people using anticholinergic medicines need their medicines regularly checked by doctors as anticholinergic medicines may have side effects.

## Prevalence and Predictors of Multiple Medicine Use in an Ageing Population with Intellectual Disability in Ireland

M. O'Dwyer, J. Peklar, M. McCarron, P. McCallion & M. Henman

Older people with intellectual disabilities often use many medicines to treat health conditions. We need to have information about the patterns of medicine used in people with intellectual disabilities as they get older.

There is a study called IDS-TILDA in Ireland that has 753 people with intellectual disabilities over the age of 40. We looked at what type of medicines people were taking and what health conditions they had. We used this information to try to find out who was more likely to use more medicines.

We found that most people reported taking medicines. One third of people used more than 5 medicines and one in five used more than 10 medicines. Older people , people living in residential settings and people with severe or profound intellectual disability were more likely to take 5 or more medicines. People who had mental health problems were more likely to use 5 or more medicines.

Overall, we found that a lot of people were taking more than 5 medicines. We recommend that it is important that doctors review the number and types of medicines that people are taking to make sure they are all needed.

# Symposium 3.14 Interventions to Ameliorate Emotional Difficulties

## Group cognitive behavioural therapy for people with Asperger Syndrome who have problems with anxiety:  the initial results of the PAsSA pilot treatment trial

P.E. Langdon, G.H. Murphy, E. Wilson, L. Shepstone, D. Fowler, D. Heavens, A. Malovic, A. Rose & L. Mullineaux

Aims: We tested whether group cognitive-behavioural therapy (CBT) can help people with Asperger syndrome who have problems with anxiety.

Method:  Fifty-four people were given treatment.  The order they got treatment was decided at random. They were asked questions about how they felt before and after treatment by people who did not know when they got their treatment.

Results: The findings suggest that group CBT could be helpful for people with AS.

Conclusions: We need to do a bigger study to make sure CBT is helpful.

## Group cognitive behavioural therapy for people with Asperger Syndrome who have problems with anxiety: views of the people with Asperger Syndrome

A. Malovic, P.E. Langdon, G.H. Murphy, E. Wilson, L. Shepstone, D. Fowler, D. Heavens, A. Rose & L. Mullineaux

This study is the second part to the PAsSA trial. A lot of people with Asperger Syndrome (AS) have some problems with anxiety, which is when a person worries too much, and sometimes has tummy and body aches from doing so. The PAsSA trial wanted to find out if being part of a group cognitive behavioural therapy can help people who have these problems with anxiety. This second part to the study was asking the people about their experiences as participants of the study. What they liked and what they didn't like about the group work. Each participant met with the other group members in the treatment group for one session per week for 21 weeks. We found that: - Each prison's view was different.

- Some thought it was a good thing to take part in.
- Some did not think so.
- A lot of people said they would have like to have individual therapy, being part of the group was not always a good thing.
- Also people felt that some parts of the therapy were very good, but others not so.

# Emotion-based social skills training for children with autism spectrum disorder and mild intellectual disability: a controlled intervention study of 75 children in Australian primary schools

B. Ratcliffe

# Symposium 3.15 ASD: Diagnosis and Behaviour

## Inclusion in diagnostics/health care: a multiprofessional approach for diagnosing autism in adults with intellectual disabilities

T. Bergmann, M. Heinrich, A. Diefenbacher & T. Sappok

## Diagnosing autism in people with multiple disabilities: introducing a new instrument

G. de Vaan, M.P.J. Vervloed, H. Knoors & L. Verhoeven

Someone with an intellectual disability, and a seeing or hearing disability as well, has multiple disabilities. These people show difficulties in behaviour that look like an Autism Spectrum Disorder (ASD). Behaviour of people with ASD looks like the behavior of people without ASD. This makes it difficult to diagnose ASD in people with multiple disabilities.

OASIS is a new tool that can help diagnose ASD in this group. In 60 participants it was tested to see of OASIS is able to diagnose ASD in people with multiple disabilities.

## Factors predicting social dysfunction in people with autism: a multiple mediation model approach

L.O. Lundqvist

## Predictors of challenging behaviour among specialist mental health service users with intellectual disability and autism

L. Underwood, J. McCarthy, E. Tsakanikos, T. Craig, P. Howlin & N. Bouras

Aims: The study aimed to find out which people with intellectual disability have high levels of challenging behaviour.

Method: We talked to 92 people with intellectual disability. We asked their carers about challenging behaviour. We also asked about mental health problems and autism.

Results: We found that people with autism had more challenging behaviours than people without autism. This was more important than other factors like age and severity of intellectual disablity.

Conclusion: people with intellectual disabilty and autism need more support to help reduce their challenging behaviour.

## Symposium 3.16 Health Interventions for People with IDD

### Developing Guided Self Help packages for people with intellectual disability

E. Chaplin, J. McCarthy, L. Underwood, S. Hardy, P. Cronin & L. Peyton

We have written a book for people with intellectual disability.

The book helps people who are feeling upset.

The book is called the SAINT (Self-Assessment and INTervention).

People with intellectual disability helped to write the SAINT.

The SAINT is a self-help work book.It can be used to write down feelings.

The SAINT can help someone recognise their feelings.It can let others know when someone is feeling upset.

The SAINT describes ways of coping with feelings.

People with intellectual disability can use the SAINT with help from someone they know well.

We hope the SAINT will help people feel better.

# Functional walking capacity following participation in a physical activity and exercise intervention

K. Lante, R.J. Stancliffe, G.M. Davis, A. Bauman, S. Jan & H. Van Der Ploeg

## Psychosocial outcomes following participation in a physical activity and exercise intervention

R.J. Stancliffe, K. Lante, G.M. Davis, A. Bauman, S. Jan & H. Van Der Ploeg

Aims:

A lot of people with intellectual disability do little exercise. We looked at the effects of doing more exercise. We asked people about their attitudes to exercise and about their wellbeing.

Method:

Adults with intellectual disability joined one of three groups:

(1) small group exercise,

(2) individual lifestyle exercise, or

(3) a control group with no change in exercise.

We asked them about their attitudes to exercise, their wellbeing and their mood (feeling happy or sad).

We also asked carers about some of these issues.

We asked these questions before they started doing regular exercise, again 3 months later and yet again 6 months after that.

Results:

People in the lifestyle exercise group had more positive attitudes about exercise after 3 months of doing exercise.

There was no change in people’s mood.

This might have been because most people were already quite happy before starting exercise.

Conclusion:

Doing exercise was linked with more positive attitudes about exercise.

# The feasibility and reliability of physical fitness tests in children with a moderate to severe intellectual disability

M. Wouters, T.I.M. Hilgenkamp & H.M. Evenhuis

# Symposium 3.17 Health, Ill-Health and Diagnostic Systems

## From ICD-10 to ICD-11 and people with disorders of intellectual development (PWDID)

S. Cooray, R. Alexander, A. Roy, K. Purandre, J. Devapriam, A. Wijeratne, H. Kwok & J. Mendis

## The ICD-11 and people with disorders of intellectual development (intellectual/developmental disability) (PWDID): a question of clinical utility

S. Cooray & K. Purandare

## Abnormality versus normality in a perspective of inclusion: a clinical anthropological approach

J. De Groef

# Symposium 3.18 Death and Bereavement in IDD

## Fit for purpose? Examining the occurrence of persistent complex-bereavement related disorder in intellectual disability

S. Guerin, K. Lockhart, J. McEvoy & P. Dodd

## The lack of reasonable adjustments as a contributory factor to premature death

A. Marriott, P. Heslop, M. Hoghton, P. Fleming, P. Blair & L. Russ

In England, a study looked at whether some people with intellectual disabilities are dying too soon. We looked at all the deaths of 247 people with intellectual disabilities in an area of South West England.

We looked at why people with intellectual disabilities died sooner than people in the general population. We found that one of the problems was that reasonable adjustments were not made. Reasonable adjustments are the changes people or services must make so disabled people can use services as easily as everybody else. This is the law in England. Our study showed that not everyone makes reasonable adjustments for people with intellectual disabilities.

When reasonable adjustments were made for someone it helped them to get better care. However reasonable adjustments were not made for everybody who needed them.

## Disseminating research findings to ensure an impact in practice and policy

A. Marriott, P. Heslop, M. Hoghton, P. Fleming, P. Blair & L. Russ

In England, a study looked at whether some people with intellectual disabilities are dying too soon. We looked at all the deaths of 247 people with intellectual disabilities in an area of South West England. We made some suggestions about how services could be changed. These changes would help people with ID live longer, healthier lives. We have been working to tell people about what we found and what we think needs to change. We have written articles about our findings. We have been to lots of places to talk to people about our findings. We have made videos about our findings and a DVD presenting the findings through stories. We have had meetings with people who run health services to talk about making changes. We have used the internet and twitter to tell people about all the things we are doing. Different people need information in different ways. We need to make sure that people who run health services make a plan of what they are going to change. We have found the internet and twitter are good ways to share information with people.

## A survey of psychodynamic psychotherapy outcomes for a specialist learning disability loss and bereavement service

G. Parkes & R. Akther

# Theme: Inclusion

## Inclusive research using a participatory action approach

V. Cobigo, P. Grandia, H. Ouellette-Kuntz & L. Martin

## Inclusive research with people with disabilities – a structured literature review

T. Frankena, J. Naaldenberg & H. van Shrojenstein Lantman-de Valk

## Self advocates shaping support services

R. Hopkins, G. Minogue & B. Hogan

## The sheltered workshop counselor: Inclusive Research Network in Finland

P. Tiihonen, S. Kekki, P. Kukkaniemi & H. Heikkilä

# Symposium 1.0 Law and Abuse

## Supporting people with intellectual disabilities who have experienced abuse or trauma through psychotherapy: a model of disability psychotherapy

N. Blackman & R. Curen

## How Circles of Support and Accountability are able to deliver an effective community-based intervention for Adolescents with Intellectual Disabilities who exhibit Sexually Harmful Behaviour

R. Curen, N. Blackman & S. Hillyard

We are aware that some young people with intellectual disabilities sometimes commit sexual offences. In order to help with this problem Respond has developed a service called a Circles of Support and Accountability (CoSA). The service is designed to reduce isolation and help stop people committing more crimes. We wanted to know if this service was successful so we asked key people for their thoughts.

We set up 3 Circles and asked 9 people whether they had noticed any changes since the start. This paper looks at what the people in the Circle did, who was in it and what did it manage to do about offending.

We found out that the Circle was able to help people to feel less isolated by enhancing the person to feel more connected and in control of the harmful things they sometimes do.

## Independent Sexual Violence Advisor's for People with Intellectual Disabilities: Results from the service

R. Curen, N. Blackman & A. Rose

Respond is an organisation that supports people with Intellectual Disabilities who are victims of sexual violence. We know that people need better support than they often get. Respond employs an Independent Sexual Violence Advisor (ISVA) to help victims and their families. She helps by making sure they understand what is happening and by helping them to be safe in the future. The ISVA works closely with other people in the persons network.  We looked at information, such as where people live and why they were referred, so that we could see if the service was working well or not. We asked people what they thought of the service. We found that the ISVA service is a great way to help people who have had really bad things happen to them. We also found that people really liked the service and would recommend it to others.

## Symposium 1.1 Law and Restraint

### Swedish legislation on restraints in community services for people with ID

P. Björne

In Sweden, the law says that people with intellectual disabilities cannot be forced or restrained in their home or at the daily activity center. People with intellectual disabilities have the same rights and protections as everyone else. Inspectors visit services to make sure that staff and managers follow the law. Still, harmful restraints are sometimes used. We have to know why. Staff are afraid that persons with ID will come to harm if restraints are not used. Sometimes inspectors accept harmful restraints, sometimes they don't. This makes it difficult for staff and managers to know what to do when they feel that a service user is in danger. It is dangerous for service users when staff do not understand how to interpret the law. Maybe Sweden needs a new law that is clearer to understand.

## Using and reducing restrictive measures in adolescents with mild intellectual disabilities: a survey of staff members

V. DÖrenberg, A.de Veer, A. Francke, P. Embregts, M.van Nieuwenhuijzen & B. Frederiks

## Using restraint in the care of people with intellectual disabilities: the role of the law in different countries

D. A. de Waardt, B.J.M. Frederiks, I.C.H.Clare & A.J. Holland

## Freedom restrictions in a Dutch care organization for people with intellectual disabilities: prevalence and factors

B. Schippers, C. Schuengel, M.van Nieuwenhuijzen & B. Frederiks

## Symposium 1.2: The Law and Offenders with IDD

### The Right to a Fair Trial: is Article 6 a reality for defendants with IDD?

R. Forrester-Jones & G. Murphy

Aim: UK law says that all Defendants (people who are told they have done something against the law) should be treated in the same way in court. But we think that UK courts including the judge who makes decisions still do not understand disabilities. This sometimes means that people with disabilities may go to prison when they should not.

Method: we looked at criminal cases involving people with disabilities. We did this by looking at the internet.

Results: we found that the term 'learning disability' is used in different ways in court reports. This makes it difficult to study this subject. We found that the difficulties people with disabilities have are often not taken seriously in court. This means that sometimes people with disabilities are convicted (told they are guilty) of crimes which they did not do.

Conclusion: we need to teach judges and other people in court about disabilities so that they can understand the difficulties people with disabilities have especially when they are in court. We also think that there should be a special court to help defendants with disabilities understand what is happening in court.

## The moral reasoning abilities of men and women with intellectual disabilities who have a history of criminal offending behaviour

E. McDermott & P.E. Langdon

Aims: We tried to understand how men and women with intellectual disabilities (IDs) think about different things, like obeying the law or keeping a promise, and whether this related to their behaviour. We asked people who had been convicted of a crime and compared their answers to people who had never been in trouble.

Method: We asked sixty-eight people with IDs to fill in our questionnaires.

Results: Men and women did not differ in the types of answers they gave, but offenders gave different kinds of answers than people who had never been in trouble. The answers people gave related to their behaviour.

Conclusions: People need to think about these things when trying to help people with IDs who get into trouble with the police.

## Assessment of co-occurring mental health and neurodevelopmental problems among prisoners with intellectual disability

J. McCarthy, E. Chaplin, L. Underwood, H. Hayward, A. Forrester, P. Asherson, S. Young, R. Mills & D. Murphy

Aim: the aim of the study was to find out how many prisoners with intellectual disability had mental health problems.

Method: We met 33 prisoners with intellectual disability. We used a special interview to find out if they had any mental health symptoms.

Results: Prisoners with intellectual disability were more likely to think about suicide than other prisoners. Prisoners with intellectual disability were more likely to have had major depression in the past than other prisoners.

Conclusion: Prison staff need to do more to find out whether prisoners with intellectual disability are feeling depressed or suicidal.

## Screening prisoners for intellectual disabilities in three English prisons

G.Murphy, J. Gardner & M. Freeman

## Symposium 1.3: The Law and Mental Health Services

### Mental health in the mainstream: including adults with ID in generic in-patient mental health services

J. Bernal, M. Atherton, S. Axby & R. Shankar

### Being closer to home is of course a good thing. Or is it?

T. Chan

We find out from the news some people with intellectual disabilities in hospital for their behaviours were treated badly. Some of these people were in hospitals far away from home. Since then most people think it is a good idea to bring these people back closer to their own homes and families. I am a psychiatrist working in a part of London, UK. The people who live there come from very different backgrounds. I am going to tell the stories of some of the people I work with who are in hospitals or are living far away. I found that some of these people and their families think moving back closer to where they come from is a good idea. But others prefer to live further away. It is important for people and the government to know that there are different views and experience. Moving people closer to home is a good thing for many people but it may not be the right thing to do for everyone.

## Sent away: 'export' of adults with ID to a rural county, the personal and economic costs

R. Shankar, V. Olotu, W. Goodrum, S. Axby & J. Bernal

The speech would identify the number of people who were placed from outside Cornwall (a county in UK) by non-Cornish care providers, the way they were placed (i.e. taking their wishes into account or not, meeting with the local services etc.) and the costs to the local services in looking after them. This is important because most times the people concerned would have lacked a voice in this sort of move. If given choices sensitively they would in all likelihood prefer to stay closer home. It also has an impact on the services provided to the local population with ID. The UK government after a major enquiry in 2011 to abuse in a hospital has clearly stated that people with ID need to be placed closer home. Thus it is bad practice to move vulnerable individuals without due consideration of the impact it might have on them and their families.

## Reforming mental health services for people with intellectual disability: the development of key priorities and a national guide for australian mental health service providers

J.N. Trollor, A. Ching, N. Lennox & J. Simpson

## Symposium 1.4: The Law, Safeguarding and Mental Capacity

### Choice, safeguarding and poor practice in residential care and supported living services for adults with learning disabilities

R. Fyson

### In your best interests? The Mental Capacity Act and people with ID

A. Marriott

This paper looks at the Mental Capacity Act. This is a law in England about how to support and protect people who cannot make their own decisions about something. We will talk about two studies. The first study found out how people were having decisions made for them. In our law, this is called 'best interests decisions’. The second study was about health care, and looked at how and why people with ID were dying. We found some examples where the Mental Capacity Act had worked really well for people with ID. We also found there were lots of problems when doctors made decisions about people’s health care. We found that they did not all understand or use the Mental Capacity Act. We will talk about some of the difficulties with this law and how people can use it to support and protect people with ID.

### Direct payments and best interests: using mental capacity legislation to extend choice for people with ID

P. Swift

A direct payment is money from a local council that a person can use to buy the support they want. Lots of people who have a direct payment think it is the best way to get the support they want. In the past, people who could not decide for themselves were not allowed to have a direct payment. The council would arrange their support instead. Now things have changed. If a person cannot decide for themselves, they can still have a direct payment so long as someone will look after the money – this is often a member of their family. We found out how this is working by talking to the people involved. They said it was good to have the money to buy support for the person. The people who look after the money need more help. We have some ideas about how to change things for the better.

### Support Planning in Practice

V. Williams, S. Porter & S. Strong

Disabled people in England often have a personal budget. That means they can plan their own support. But people with ID sometimes have problems when it comes to speaking up. Our research looked at some of these problems, by listening to real support planning sessions. We found that people with ID did not always have a strong voice. Sometimes their family member has a stronger voice than they do. But we know that there are laws in England, which say people should get good support. We talked about this with a group of people with ID. They helped us to make a DVD, which shows how people can get support to speak up about their support plan. We will show a bit of the DVD, and talk about how we did the research and worked out what it all meant.

## Symposium 2.1 The Law and Hate Crime against People with IDD

### Living in Fear: The impact of Disability Hate Crime, as reported by people with intellectual and developmental disabilities (PwIDD).

J. Bradshaw, J. Beadle-Brown, L. Richardson, C. Guest, A. Malovic & J. Himmerich

Aim:

This paper looks at hate crime.

It looks at how people with intellectual and developmental disabilities feel about bad things that happen to them.

Methods:

We talked to 24 people with intellectual and developmental disabilities.

We asked them about hate crime.

Results:

Lots of people told us about bad things that had happened.

Some people had lots of bad things that had happened to them. They talked about how bad things made them feel. They sometimes told other people about the bad things. Some people did not tell anyone.

They were worried that they would not be believed.

Conclusions:

Lots of people had to make changes to their lives.

Some people moved house.

Some people stopped using buses.

Some people said things were better now.

We think that people needed better support when bad things happened.

## Community Safety Partnership members' and Police officers' views and experiences related to disability-related hate crime – findings from focus groups.

C. Guest, L. Richardson, J. Beadle-Brown, A. Malovic, J. Bradshaw & J.Himmerich

Sometimes people with intellectual disabilities or autism living in the community have bad things happen to them because they have a disability. We wanted to find out about the views of the police and other groups which work together to keep communities safe.

We met with 40 staff to talk about:
their understanding of disability hate crime
what kind of things happen to people with disabilities
how they help people with disabilities
what stops people telling the police about crimes
what is difficulties about helping people with disabilities

We found that:
Some people thought that the guidance and law about disability hate crime was not clear nor helpful. Most people knew someone who had been victimised and said that such crimes are often not reported. The type of experiences ranged from rudeness and name calling to being physically hurt
The things that made it difficult to help victims with disabilities were:
Not enough training for the police about intellectual disabilities and autism
Not enough advocates who understand about hate crimes
Not enough help from social services. What we found helped us make a survey about the experiences of police officers.

## Police officers' views, knowledge and experiences related to disability related hate crime.

A. Malovic, C. Guest, J. Beadle-Brown, L. Richardson, J. Bradshaw & J. Himmerich

We have been finding out about bad things that can happen to people who have an intellectual disability or autism when in their local community. We also wanted know what police staff knew about intellectual disabilities and autism and how they helped people who were victims.

459 Police staff used a computer to fill in a survey. They answered questions about: whether they knew or had worked with people with intellectual disabilities or autism, their knowledge of intellectual disabilities and autism, whether they felt confident about helping people with intellectual disabilities and autism, what was difficult about helping people with intellectual disabilities and autism

We found that:
Most of the police knew or had worked with people with intellectual disabilities or autism
Some of the police had had useful training but many had not
Although knowledge was quite good there were some important things police officers didn't know
Sometimes they found it hard to know if a person had an intellectual disability or autism
Sometimes they didn't have enough time to give the right help when bad things happened We think that the police need to get to meet more people with intellectual disability and autism as part of their training.

## Living in Fear: The experiences and reporting of Disability Hate Crime by people with intellectual and developmental disabilities (PwIDD).

L. Richardson, J. Beadle-Brown, C. Guest, A. Malovic, J. Bradshaw & J. Himmerich

Most people with disabilities live in the community in the UK.
Sometimes people are treated badly by other people because they have a disability – this is sometimes called disability hate crime. We wanted to find out if people living in an area called Medway, had been victims of disability hate crime.

We met with groups of adults with disabilities and their carers and we also sent people a survey. We found that:
Not everyone had been a victim of hate crime, but one third of people had.
People who were victims had experienced more than one incident over a long time.
Different types of bad things had happened to people – sometimes people were called names or laughed at and sometimes people were hurt or had things stolen.

People that seemed most likely to be victims were:
People who were younger,
People who reported they had a mental health problem,
People who did not receive help around their home or to go into the community
People did not always tell someone else when they had been a victim of a hate crime.

Only about one third of people told the police - Some felt the Police were helpful and others found them unhelpful.

## Symposium 2.2: The Law and Offenders with IDD

### Healthcare service use and care pathways of prisoners with intellectual disability

E. Chaplin, J. McCarthy, L. Underwood, H. Hayward, J. Sabet, A. Forrester, P. Asherson, S. Young, R. Mills & D. Murphy

Aim:

The aim of the study was to understand the health needs of prisoners with intellectual disability.

Method:

We did the study at a prison in London. We met with prisoners to see if they had an intellectual disability. We also looked at their prison records.

Results:

We found 33 prisoners with intellectual disability. The prisoners with intellectual disability had more contact with mental health care services than other prisoners. The prisoners with intellectual disability were more likely to be in the part of the prison for vulnerable people.

Conclusion:

Prisoners with intellectual disability need more support than other prisoners. It is important that people with intellectual disability are recognised as soon as they come into prison.

## People with autism and the criminal justice system in England: data from the autism self assessment framework

S. Baines, A. Christie & C. Hatton

## An evaluation of the EQUIP treatment programme with men who have intellectual or other developmental disabilities

P.E. Langdon, G.H. Murphy, I.C.H. Clare & E.J. Palmer

Aims:
We wanted to see whether the Equipping Youth to Help One Another Programme (EQUIP) was helpful for offenders with intellectual and developmental disabilities.

Method:
We invited three men with intellectual disabilities (IDs) and four men with a diagnosis of Asperger Syndrome, who had been in trouble with the police, to take part in our treatment group.

Resluts:
Treatment helped change the way people thought about their problems, and helped them to understand how their behaviour affects other people.

Conclusions: The EQUIP programme could be helpful, but we need to do a bigger study.

## Adapting the delivery of the thinking skills programme for prisoners with ID

G. Murphy, N. Akinshegun, A. Giraud- Saunders & P.M. Oakes

## Symposium 2.3: The Law and Decision-Making

### An explorative qualitative study on supported decisionmaking

N. Devi

### Sterilisation of people with intellectual disabilities: issues for consideration

S. Hayes

### Possible moral contra-indications concerning fertilization treatments

M. Roovers & A. Coppus

# Health care decision-making by adults with intellectual disability and the effect of a decision-support

K. Schossleitner & G. Weber

We wanted to know how people with ID make health-related decisions. We would like to see if there are differences between people with and without ID. We wanted to know how supporters could be of help when a person with ID has to take a decision with respect to his or her health.

Interviews with these persons (living in three different housing types) were organized and they were asked how well they understood medical information. We asked them with their supporter as well as without their supporter. Moreover special capacities of importance when persons are thinking about something were assessed. We wanted to know if there are influences of these capacities on the competence to take a decision.

We found out, that people with ID often find it harder to make health-related decisions than people without ID. Support-persons were of good help and this allowed people with ID to better make a choice or take a decision. Moreover the special capacities played a role for the ability to make health-related decisions.

Our results demonstrate that people with ID can come to good own decisions with respect to their health when they get good explanation by a supporter.

# Symposium 3.1: Safeguarding and Rights of People with IDD

## Safeguarding the rights of people with disabilities: an organistional system approach

J. Chan & R. Chiavaro

## Safeguarding Children and Adults with Intellectual, Developmental and Sensory Disability from Neglect and Abuse

K. McVilly, G. Ottmann, J. Anderson, A. Roy, J. Chapman, A. Stefano &

O. Kariyawasam

Some people with disability don't get the support they need; this is called neglect. Some people with disability get hurt by people in their family and by support workers; this is called abuse.

Neglect and abuse are bad things that should not happen. Services need to work in ways so people don't get neglected or abused.

Services need to teach their staff how to keep people with disability safe, and what to do if they think people are in danger.

We asked experienced service providers about how to protect people with disability from neglect and abuse.

They told us what should be done by answering questions on the computer.

We found out the things that are important to keep people safe.

We also found out some of the things that get in the way of keeping people safe.

We found out that people with different disabilities need different types of support.

We are going to talk about the things that people told us were important to keep people with disability safe from neglect and abuse, how services can work better, and the training that staff need.

## If you can't read it...click it – Promoting access to legal information for a gentleman with Intellectual Disabilities (ID): A case study.

W. Oldreive & M.P. Waight

People with ID must understand what is happening to them. They need help. People may need help when things are written down and new words are used. Lots of people may be saying different things. Things may change all the time. There is a lot to remember.

People feel stressed.

We tell the story of a young father with ID who could not read. He was easily confused. He found it hard to remember everything. We say what happened and how we helped him understand a lot of complex legal information. The approach we used was a bit different and we want to tell you about it.

We hope that other people will do it again in order to help other people who have the same rights and needs.

## Participation: our experiences and needs - interviews with representatives of interests for people with disabilities

T. Schweinschwaller

## Symposium 3.2: The Law and Offenders with IDD

### People with intellectual disability and borderlineintelligence in Austrian prisons

J. Purzner & G. Weber

### Importance of locus of control in treating offenders with intellectual disability

M.D. Raymond

Aims: An externalised locus of control (LOC) means you believe someone else changes your behaviour. An internalised LOC means you believe you can change your behaviour, not someone else. Offenders with an internalised LOC do better in therapy and do not re-offend as much. This study looked at LOC in offenders with intellectual disability (ID). What is learned can help offenders with ID better.

Method: There were three groups. ID and non-ID Offenders were chosen from gaol. Non-offenders with ID from the community. They answered questions on LOC. The study looked at LOC in offenders with ID between the three groups.

Results: On average, offenders with ID have a higher externalised LOC compared to the other groups.

Conclusion: This study showed offenders with ID need therapy focused on internalising LOC. This would mean more therapy success. This presentation will also talk of how to internalise LOC in therapy.

# The core features of ‘good’ community support for people with intellectual disabilities who have offended, or are at risk of offending

J.R. Wheeler, A.J. Holland, I.C.H. Clare, E. Jones, C. Perez, M. Dunn, L. Gelsthorpe & J. Manthorpe

## New Legislation and new secure service for Queensland - The Queensland Forensic Disability Act (2011) and the Forensic Disability Service three years on - A follow up of all referred cases.

A. White

We need to know that any new service works. This is especially true for any service that locks people up. We need to know:

- Is it helping them not to get into trouble again?
- Is it better for these people to go there or stay where they are and to get help there?

We have a new secure service in Queensland Australia, which has its own Law. We will describe the new Law, why we have this Law, and the new service. We will describe what has happened to all the people who the new service has been asked to take. We will compare the ones that have come into the service with those who have not come in. We will look to see:

- Are they keeping out of trouble?
- Are they trying to change things for themselves?
- Are they spending more or less time in the community?
- Do they need secure care now?

We found that most people that came into the service have done well. We think those who didn't come into the service need more help where they live.

## Symposium 3.3: Public Care, Abuse and Information on the Law

### Building a profile of children and young people with intellectual disabilities in public care in Northern Ireland.

B. Kelly, S. Dowling & K. Winter

Aims: Our talk will discuss a project that aims to count how many children and young people with intellectual disabilities live in public care in Northern Ireland and find out more about their backgrounds.

Method: To collect this information we put together a survey for social workers who work with these children and young people to fill in.

Results: In our talk we will show what we found out about these children and young people including their: age, why they are in care; their contact with their families; where they live now and in the past and who helps them in their daily lives.

Conclusion: We will talk about how the backgrounds of these children and young people compare with other children in care including where they can live, the number of changes in their lives and the people in their lives.

## Sexual Abuse of Children with a Mild Intellectual Disability in the Netherlands

X. Moonen & I. Wissink

We wanted to know more about the nature of sexual abuse of children with a mild intellectual disability (MID) in the Netherlands and who these children were. We conducted two studies. In the first study we gathered information world wide, about abuse of children with MID who have been placed in institutions or foster families. In the second study we analysed cases of sexual abuse reported to the Dutch Health Authorities and we compared information of abused children with MID with information of abused children without MID. We found out that children with MID living in institutions were at a higher risk of being abused, many of them by peers. Most of the reported cases of sexual abuse were discovered only because the children spoke about the incident themselves. We now know far more about how to prevent children with MID living in institutions and foster families from being abused.

## Law of diminishing returns: what happens when people with ID need legal advice?

P. Swift & V. Mason

People with ID should get help with the law when they need it. We spoke with lots of People First groups to find out if they do. We also spoke to some families that have a person with ID. Some people needed help with things that affect everyone, like sorting out the money when someone dies. Others wanted help with things to do with their ID – like whether they are able to bring up a child. Most people did not know when they should get help about the law or where they could get it. Some people worried that if they got help it might affect other things in their life, like a service they need. Others did not have the money to pay to get help. But we also heard from people who got good help from people who know about the law. We have some ideas about making things work better.

## Symposium 3.4: The Law and Rights of People with IDD

### What do we mean by ‘choice’ and ‘independence’? A critique of the implementation of the UK policy of ‘Personalisation’ in services for people with intellectual disability

R. Fyson

### Adults with intellectual disabilities: living independently in China

J. Li

### UNCRPD Article 12 ‘Equal recognition before the law’: Are we ready to uphold it for all Australians, including those rarely heard, those with severe to profound intellectual disability?

J. Watson, E. Wilson & N. Hagiliassis

## Legal definitions of intellectual disability: do they work?

S. Whitaker

Recent work has shown that we cannot measure intelligence or IQ as well as we used to think we could. If a court of law is deciding if somebody has an intellectual disability the court will usually look at what the government or other “important" people say an intellectual disability is. When these definitions of intellectual disability are looked at there seems to be a problem because the people who wrote them seem to think that we can measure IQ very accurately.

This will mean that some people may not be given the right IQ score when their IQ is tested, so the court may think they have an intellectual disability when they don't, or the other way round.

## Symposium 3.5: Parents with IDD

### Being a mother with intellectual disability in Maltese society: do you have what it takes?

C.Azzopardi Lane

Women with intellectual disability have the right to become parents as do non-disabled persons. Often mothers with intellectual disability require support to take care of her child/ren. I asked: What difficulties do mothers with intellectual disability come across when taking care of their children? What support do these mothers feel they need? Is someone giving them this help, if so who?

I asked 1 mother with intellectual disability and her family about their experience. I found that woman with intellectual disability do not know many things about sex, especially about contraception. These women need to learn how speak up for themselves and need to be more involved in the life of their children. Mothers with intellectual disability in Malta do not have help except for their family members. They also need money to take care of their children and if they are working this is very difficult.

### Pseudoscientific measures and practices in appellate level and higher child welfare cases involving parents with IDD

M. Feldman & E. Callow

## Toward child protection governance that better supports mothers with intellectual disabilities

R. Greimel

Aim: I wanted to find out how mothers with intellectual disabilities were treated in an Australian child protection system that agrees with the United Nations Convention on the Rights of Persons with Disabilities.

Method: I talked with ten mothers with intellectual disabilities about their experiences. I looked at:
whether their experiences were the same or different;
what child protection workers had written about the mothers and why, and;
the laws about child protection and what workers should be doing to help children and their families.

Findings: I found that how the workers thought about the children and their mothers might have:
made a difference to the workers' decisions;
made a difference in how they treated the mothers.
This may have made the mothers' experiences more difficult.

Conclusions: Even when a country agrees and signs the United Nations Convention on the Rights of Persons with Disabilities, mothers with intellectual disabilities might still experience difficulties and not be treated right. Changes to some laws and practices might help make their experiences better in the future.

## Parents with intellectual disabilities and the fight to retain and sometimes gain custody of their own children

H.B. Sigurjónsdóttir

## Symposium 3.6: Abuse and Mistreatment of People with IDD

### Abuse prevention: building ethical and respectful cultures in group homes

P. Frawley & C. Bigby

### The crime of domestic violence: what women with intellectual and developmental disabilities say about their abusive relationships

M. McCarthy, S. Hunt, K. Milne Skillman & G. H. Murphy

What is this research about? Domestic violence is when people get hurt by someone they are in a relationship with. This can be a marriage or being boyfriend and girlfriend or two people of the same sex. Our research is about women with learning disabilities getting hurt in relationships. How did we do this research? We spent a long time with 15 women with learning disabilities. They told us about what had happened in their relationships and how they got help. What did we find out?

- That the violence often goes on for a long time and some of the women got very badly hurt.
- That the women had often seen violence from their fathers to their mothers when they were young
- That it was very hard for the women to leave their husbands or boyfriends
- That the men usually did not have learning disabilities, but they did have other problems Why was it important to do this research? Because women with learning disabilities often need help to avoid or get out of violent relationships.

## The crime of domestic violence: the attitudes and practices of professionals who support women with intellectual and developmental disabilities

M. McCarthy, S. Hunt, K. Milne Skillman & G. H. Murphy

What is this research about? Domestic violence is when people get hurt by someone they are in a relationship with. This can be a marriage or being boyfriend and girlfriend or two people of the same sex. Our research is about women with learning disabilities getting hurt in relationships. When this happens, they can ask for help. The police, social workers, nurses and doctors and other support workers might help them. We want to ask those people what they know about domestic violence.

How did we do this research? We asked lots of questions of lots of people. They were all people who might help women when they get hurt in relationships. Then we put all their answers together and looked at the most important things they said.

What did we find out? We haven’t finished yet, but by the time of the conference we will know what they said. Why was it important to do this research? Because the people who help women with learning disabilities need to have a good understanding of the problems the women face and how they can best help them.

# Analysis of Quality of Life of People with Intellectual Disability in Community in Cornwall UK Two and Eight Years Post Institutional Abuse and Mistreatment

R. Shankar, S. Axby, J. Bernal & W. Goodrum

In 2006 ID hospitals in Cornwall UK were closed due to worries of abuse of 24 vulnerable patients there. These 24 patients were moved to various placements of their and their family choice. Currently 20 live in Cornwall with support. The speech is about understanding how the 24 were coping two years after the move and more recently. The speech would look to show what worked well and what did not. It would identify the types of support needed and the costs for providing a complex individual with ID the correct structure. Recently given the concerns of abuse in other hospitals in UK and the government's wish of not wanting to see an person with ID in a hospital we believe our speech will help share our learning with others.

## Theme: Living in the Community

## Symposium 1.1 Community Living Around the World

### Community Living in Australia and the UK – three steps forward, two steps back?

C. Bigby & J. Beadle-Brown

## A quick tour of institutions and community-based services in North America

V.Cobigo & E. Callow

Aim:

We will talk about services for adults with IDD (which means 'intellectual or developmental disability’) and who is doing them in Canada, the USA and Mexico.

Method:

Canada: we will talk about services in different parts of the country, and what we learned about making services better for adults with IDD in Ontario, Canada.

America: we will talk about what happened when America closed almost all institutions, what has been hard about this and what is happening for people who have IDD and live in the community.

Mexico: we will talk about what people have written about life for people with IDD and how they are trying to get better services.

Results:  Services people with IDD use are different all over North America. Some places still use institutions, some are closing them and helping people live in the community, some have already closed them all and are now studying how things have turned out.

Conclusion: Not all institutions are closed in North America and even where it is, there is a lot of work to do so the available services are good and useful to people with IDD and help them feel at home where they live.

## Current trends on community living in the Nordic countries

J. Tøssebro & I.S. Bonfils

## Current research findings on adults with ID in Taiwan: comprehensive review and future direction

K. Wang

# Symposium 1.2 Progress in Leaving the Institutions in Europe

## Moving towards a personal budget system in the Czech Republic - successes and challenges

J. Šiška

Many people in Europe still live in institutions. However this is changing in many countries because of the UN Convention on the Rights of Persons with Disabilities. This presentation will look at where people with intellectual disabilities live in the Czech Republic now and the type of services they get. It will also look at how this has changed over time. The law has changed recently so that people can now get a direct payment and have some control over the help the receive. The presentation will talk about how well direct payments are working so far. It will also talk about what is needed to help more people with disabilities in the Czech republic live in the community.

## Responding to the needs of people left within institutions – A lesson from Bucharest

M. Kerr & C. Yeoh

Many people with intellectual disabilities in Europe have now moved from institutions to the community. However, there are still many people with intellectual disabilities living in institutions. We are members of a charity. Our charity has visited an institution in Bucharest, Romania many times to speak up for the rights of people living there. We found people had: very bad carevery little supportno chance to live a good life. We will tell you in our presentation what we did to try to help. Reporters from newspaper and television began to write reports and show programmes about the bad care. The institution would not allow us to visit after this. We asked groups like human rights organisations, professionals, scientists and government groups to help us tell the world about the bad care. Some groups helped more than others. Also, it was hard for groups in different countries to work together.

At the end of our presentation, we will talk about: what we learned from working with all the groups to change things how we can work better together to stop very bad care in institutions.

## Responses to a reconfiguration of disability support services in Ireland⍰

C. Linehan, S. Craig, M. Kerr, C. Lynch, R. Mc Conkey, S. O’Doherty, A. Staines, M. Tatlow-Golden & M. Walls

Disability support services are changing in Ireland. The Irish government recommends disability service organisations: close institutions support more people with intellectual disabilities in the community. We need to have information to help make these changes. For example, we need to know: What do people with disabilities, their families and staff really think about moving to the community? To find out the answers we did 22 focus groups. A focus group is where people come together to talk and answer questions.  We also did interviews with 43 people.
We talked to: people with intellectual disabilities, their family members, staff who support themmanagers of services. We also talked to people who have a say about disability services in Ireland. In total, we talked to 219 people. Most people we talked to thought the changes were a good idea. However, people did not always understand the changes. Also, people were not sure if there would be enough money and staff to support people in the community.
We recommend that: The government and people who are changing disability support services tell people their plans in a way everyone can understandThe worries and fears of people about the changes are listened to.

## Development and outcomes of community-based services in Hungary

A. Turnpenny & J. Beadle-Brown

This study compares the characteristics and quality of life of people with intellectual disabilities who live in institutions and group homes in Hungary. We selected 120 people who lived in institutions and group homes in Hungary to take part in the research. We made sure that we compared people who had similar needs and abilities in each type of service. We asked staff to fill in a questionnaire about people's life. We also visited each service to talk to people and find out more about their life. We found out what people did during the day, if they had friends and kept in touch with their family, what choices they had, what medicines they were taking, and how staff supported them. We found that people who lived in smaller homes had a better life than people who lived in institutions. They had more choice and did more activities. There was less to do for people who lived in villages. Many people were taking medication. We will discuss what the Government and services in Hungary could do to help people intellectual disability to have a better life.

# Symposium 1.3 Ensuring Good Quality Care

## Day to day care by support staff in group homes: testing the Quickscan Strength-Based Approach

M. Dieker, P. Helmond, C. Huitink, I. Vermaes & P. Embregts

## What's your opinion? The experience of therapeutic climate in a treatment facility for adults with mild intellectual disability and severe challenging behavior.

P. Helmond, I. Vermaes & P. van der Helm

It is important to know how clients experience living in a group home for people with intellectual disabilities and challenging behavior. This information can be used to improve the living conditions of the clients in the group home. In an interview clients were asked to give their opinion about living in their group home. The questions were about how they experienced support, opportunities for growth, repression and sphere. We found that most clients were able to complete the interview. Clients provided important insight into their living experiences in the group homes. The living experiences differed between group homes. Some clients were negative about their group home while others were positive. We found that most clients experienced repression and a negative sphere. Clients told us they felt locked up and experienced a lack of freedom. Clients also told us they experienced feelings of unsafety, for example aggression, bullying, drug use. The results will be used by the management of the facility and the group homes to improve the living conditions for clients. In a while we will ask clients again about their experiences in the group home. We hope that the living conditions in the group homes have improved.

## Staff-Client interactions: the implementation of a Strength-Based Approach

C. Huitink, P.J.C.M. Embregts, J.W. Veerman & L. Verhoeven

We need information about the contact between support staff and people with intellectual disabilities. Then we can check how people react to the contact with support staff. Support staff videotaped themselves working in a group home. In total we examined 151 videos. Our speech is about these videos. We looked at four important behaviors of support staff. These behaviors are called a strength-based approach. A strength-based approach is about positive contact with clients. For example, staff behavior like complimenting a client. We found that support staff behaved this way just a few times. Staff behavior was different in contact with one or in contact with more clients. Also, support staff let some clients do more things on their own. How support staff should behave to clients must be part of staff training.

## Influencing youth's beliefs about their potential to change in residential care by using the on-line intervention Change Your Mindset.

F. Verberg, P. Helmond, D. Yeager, I. Vermaes & G.J. Overbeek

There is a need for interventions to improve the sense of competence in youth with intellectual disabilities. We will try to obtain this by teaching youth a 'growth mindset'. People with a growth mindset think that all people can change, learn new things and can get better at things. A growth mindset can be helpful to fulfill your potential. We will briefly demonstrate the online intervention Change Your Mindset that teaches youth this mindset. To find out whether youth with intellectual disabilities commonly have a growth mindset or a fixed mindset we developed the 'Change Beliefs Questionnaire'. The speech will be about this questionnaire. The questionnaire consists of 30 questions about the mindset. We asked 60 youth with intellectual disabilities (12-18 years) to complete the questionnaire. Data is currently being collected. We expect to find that this questionnaire is a good way to check the mindset of youth with intellectual disabilities. We also expect that youth with a growth mindset feel more empowered, use more positive coping strategies and show greater persistence compared to youth with a fixed mindset.

# Symposium 1.4 Parents with Intellectual Disabilities

## The cooperation between social network members and professionals for parents with intellectual disabilities: insights in protective possibilities

J. de Kimpe, S. Kef & C. Schuengel

Social support is very important. We want to promote the cooperation between professionals and the social network of parents with intellectual disabilities. Therefore we want to know more about protective possibilities. With knowledge of the members in the network we can improve the support for parents with ID. This knowledge can also be helpfull for the position of the parents in society.The speech is about the results from this study. We interviewed 14 network members individually or in groups. We also interviewed 9 professionals in a group. With the information of the interviews, information from books and articles, we made a questionnaire. Some topics of 44 questions were: types of support, quality of the relation between network members and the parent, task division between network members and professionals. From 170 questionnaires we send to network members 122 were sent back. We found that family network members are especially important in supporting parents with ID. They want to be heard. The cooperation with professionals needs to be better. To know how an intellectual disability influences daily live is important. It can be helpfull for the cooperation between network members and professionals. Telling each other which support you give or want also improves the cooparation.

## The Role of Intelligence and Experience of Trauma and Abuse for Maternal Sensitivity in Mothers with Intellectual Disability and their children´s Attachment: A Matched Comparison Study

T. Forslund, M. Fransson, L. Springer, L. Lindberg & P. Granqvist

We need more information about the parenting of parents with intellectual disability (ID) and their children´s development. An important part of parenting is to respond sensitively to children´s signals. Parental sensitivity affect children´s security in the relationship with the parent. There is only limited information on ID-parents sensitivity towards their children. Also, there is no information about their children´s security in their relationships with the parents. Also, we need more information about factors affecting ID-parents sensitivity and their children´s security. Is the parents´ intelligence important? Is it important if parents have experienced traumatic experiences?

We interviewed 23 mothers with ID and their children. We also interviewed 25 mothers with normal intelligence and their children. We asked the mothers if they had experienced traumatic experiences. We interviewed the children about security in handling being away from parents. We observed mothers sensitivity towards the children when playing together. Mothers and children also did intelligence tasks.

We found out that:
Many children to mothers with ID are secure
Maternal intelligence were not important for maternal sensitivity and child security
Traumatic experiences were important.
Mothers with ID who had experienced traumas were less sensitive and had less secure children.

## The effect of Videofeedback Intervention (VIPP-LD) on sensitive discipline by parents with intellectual disabilities

M.W. Hodes, M. Meppelder, S. Kef & C. Schuengel

We came up with a project about 'What works for parents with intellectual disabilities?'. We developed an intervention program using video, called: 'Videofeedback Intervention on Sensitive Discipline for parents with learning difficulties (VIPP-LD)'. With this program, parents learn to support their child in a positive way. But they also learn to be strict if necessary in a nice way. We filmed the parent and child at home:

When they were playing together
When they were having a meal
And in a situation that the parents feels difficult

We also asked the parent to fill in a questionnaire about having stress. And we looked at the way parents helped their child. In our project, 85 parents are included. Half of the group got the intervention program with video (VIPP-LD). And the other half of the group of parents got the regular support of the care organization. In this way we could compare the two groups. We found out that parents reported less stress after the program with video-support. We also found that for parents who are having more difficulties in childrearing the video support was more helpful.

## Mindset of staff supporting parents with intellectual disabilities; The association with working alliance and parental intentions to ask professional support

H.M. Meppelder, S. Kef, M.W. Hodes & C. Schuengel

We need more information about the ideas of staff who work with parents with intellectual disabilities (ID). This is also called mindset. Does staff think that these parents can grow in their parenting skills? How good is the quality of their relationship with these parents? We also need to know if there are relations between: The ideas of possible change (mindset) Quality of relation between staff and parents Support seeking of parents ID Staff filled in questionnaires, parents were interviewed. We also asked staff on the social, communication and daily living skills of the parents. In this project, we have information on 76 pairs of staff-and-parent. We found out that: 56% of the staff thought that parents with ID could change their parenting skills  If parents had less (social, communication and daily living) skills, the quality of the relationship between staff and parents was less good. But when staff believed more that parents could  change/grow this association was smaller. When staff was more thinking of change/grow in parents, these parents waited less long to ask for support when they needed it.

# Symposium 1.5 Staff Support for People with Severe ID

## Quality of communication support for people with intellectual and developmental disabilities living in supported accommodation settings.

J. Bradshaw, J. Beadle-Brown, J. Leigh, R. Whelton & L. Richardson

Aim: Good support for communication is important. This paper looks at how staff communicated with people with severe and profound intellectual disabilities.

Methods: We found out about communication in different ways. We used some questionnaires and we spent time watching how people communicated. We also looked at support for activities and support for people with autism.

Results: Staff communication was often poor. Staff told us that many people they supported did not use speech. Most people needed staff to use signed communication, symbols, objects and gestures as well as speech. Most people did not get this communication support.

Conclusions: If people had good support in other areas, they had good support for communication.

## Developing positive relationships for adults with severe and profound intellectual disabilities

H. Johnson, C. Bigby, T.Iacono, J.Douglas & S. Katthagen

Everyone needs to have relationships. These need to be with family, people we work with, and friends. Having relationships makes life more fun. People who have intellectual disabilities and difficulty communicating have difficulty making and keeping relationships. They often only have relationships with staff and family members. This study look at training staff working in day centres in Australia about how to have positive relationships and how to help people in the community develop relationships with people with an intellectual disability. We will talk about the changes we saw in the staff after training and what the staff said about the training.

## Quality of life and quality of support for people with severe Intellectual disabilities and Autism.

L. Richardson, J. Beadle-Brown, J. Leigh, R. Whelton & J. Bradshaw

People with severe intellectual disabilities and autism deserve a good life with the chance to learn new skills and try new things. To do this they need good support from staff.

We wanted to find out what kind of life people with intellectual disabilities and autism had and what support they received from staff.

We visited the homes of lots of people with severe intellectual disabilities and autism. We asked the staff and their managers about how they supported people. We also spent time watching the support that was given and looking at what people did during the day and how they communicated.

We found: Not many people with a severe intellectual disability and autism had good support from staff that helped them to be involved in activities and relationships with other people. Staff did not always use the best way to communicate with the people they supported. Some people had good support from staff to help with their autism. Other staff did not seem to understand how to support people with autism in the best way. We will tell you how the quality of support given to the people we met affected their quality of life.

## Manager and staff perspectives of skilled support

B. Whelton, J. Leigh, J. Beadle-Brown, L. Richardson & J. Bradshaw

In England most people with intellectual disabilities live in the community, including people with very severe disabilities.  Staff need to be skilled to support people well. This paper looks at what managers and staff think about skilled support.
We asked managers in 35 services for people with severe intellectual disabilities about their job and the way that people were supported in that service.
We asked them about how they helped staff be support people well. We also asked them what they thought made staff skilled.
We also asked staff to answer some questions.
We asked them about their experience, their training and what they think about skilled support.
93 staff returned the form. We will tell you what the staff and managers said about skilled support  - whether they think they are skilled and what the difference is between skilled and unskilled staff.
We will look to see any differences between what they told us and what we saw when we went to the services.
At the end, we will talk about how what we found helps us understand what is important to help staff support people well and what we can do to help staff be more skilled.

## Symposium 1.6 Improving Personalisation of Services in Ireland

### Supporting the implementation of personalised services and supports in Ireland

F. Keogh & O. Cosgrove

Our organisation is working to help disability services in Ireland to change so that they can provide support for each person in their service in a way that is tailored just for them. We have given money and training to 110 projects to help them support the people who use their services by working out with each person what they need to have a good life and helping them to get it. We checked on the differences this was making in the service by: asking the people who provide the service a set of questions in an interview; collecting other information on how the people in the project were getting on; using this to work out a score for each project; asking people with disabilities in the service what difference it made for them. We have found that because of the funding and training that was given, over 500 people with disabilities are now getting supports that help them live the life they want. Some of the thing sthat help the services to change are having strong leaders, really listening to each person with a disability, getting training and having targets for change.

## An evaluation of personalised day supports for young people with intellectual disabilities

R. Wynne, D. McAnaney, I. Jerrares, C. Dolphin & N. Dowling

15 projects in Ireland are changing the day services they provide to young people with intellectual disability. They work out with each person what they want to do in terms of getting a job, getting more education and training and what ways they like to have fun. To find out if this was a good way of supporting people, we asked 40 young people who were getting this type of support what difference it made to their life. We also asked 20 people who were not getting this support the same questions. We asked the people running the service what support they thought each person needed and what changes they had made in their service to provide new support for each person. We found that when we compared the people who got the new supports with the people who didn’t, the people who got the new supports knew more about their rights, they were more involved in their local community and they had more skills to help them get a job. This new way of providing supports also seems to cost less for the service. These services are an example of how good changes can be made in services.

## An evaluation of alternative respite models in Irish disability services

S. Guerin, F. Keogh & P. Dodd

We wanted to find out two things:

1. in all the papers that are written about respite what do they mean when they use this word?
2. do new ways of providing respite work well for the people who use the new service?

We looked at all the papers that have been written so we can describe what is meant by the word respite. We are also asking 60 families who are using new respite services and the person they support what they think of the new service. We want to know if it helps the person to be more involved in their community and we want to know if it helps out the family. Another group of 25 families who are not getting this new service will be asked the same questions. We will compare the answers we get so that we can find out what difference the new service makes. We will ask the people who provide the service what the new service costs so we can compare this with what the other service costs. We will use the information we find out to help improve the respite services that families and people with disabilities get in Ireland.

# A process model of the organizational transformations needed for the personalization of housing and accommodation supports

R. McConkey & F. Keogh

Financial grants were given to 21 Irish services to help over 200 persons to move to more personalised accommodation and support. We wanted to find out what were the factors in a service tha thelped them to be successful in this change and what were the difficulties. The senior managers of the services in the study were asked their opinions on this question. We used the idea of an engine to explain the things that helped make change happen and to show how important different things were to making change happen. The most important thing was a change in what is called the culture of the organisation. That means how everyone working in the service thinks and behaves. Four other things were important to make change happen: support from the organisation that gave the grants (called Genio), as well as changes in the opinions of staff, people using services and relatives. Other things that were important were: communication; finances; housing and community contacts. This model can be used to understand changes that different services need to make if they are supporting people with disabilities to move and have supports that are more tailored to them.

# Symposium 1.7 Special Olympics and Inclusion

## Promoting inclusion through Special Olympics Project Unify: an evaluation in four European countries

S. Dowling, R. McConkey & D. Hassan

## Community-based approach to address health disparities among Special Olympics Athletes

E. Ispas, B. Koehler, K. Kiss, R. Moscato & A. Shellard

Special Olympics (SO) has a new 'Healthy Communities' initiative. It works across the world in 14 sites across nine countries.

In Romania the focus is on educating family members and healthcare professionals. They also send text messages to athletes to remind them to keep appointments. Nearly 1,000 people have involved and we found out what they thought about the project.

Most family members strongly agreed the information was useful. They have started to adopt healthier lifestyle changes for their family.

Most healthcare providers and students felt the training made them more comfortable working with people with ID.

The text messages helped some athletes and we are learning how to get better at using new technologies.

# Special Olympics Unified Sports® Football: Empowering girls and women on and off the pitch

S. Menke & M. Braycich

Often girls and women with intellectual disabilities do not have opportunities to play football. We brought them together with other girls and women who did not have intellectual disabilities to play football in what we call Unified Sports. We did this in three countries: Serbia, Hungary and Ukraine.

First we needed female coaches. If you are a girl or a woman it is much easier to have a woman as your coach. She will understand your needs better and you can see that also women can be successful and a good leader.

We recruited 30 female coaches who led 22 teams.
Around 150 girls played on the teams; aged 12 and 19 years old. They trained at least once a week and took part in monthly competitions.

They all said they liked to be on the teams and they want to continue. They also said it was really important to have female coaches. After this success, Unified football teams are happening in more countries today.

# Healthy Athletes: International comparisons of the health of persons with intellectual disability.

A. Shellard & R. McConkey

People with intellectual disability often have poorer health.
Special Olympics has started a Healthy Athletes project to find out more about people's health and what could make it better.
They check on the health of athletes taking part in competitions all over the world.
Information on over one million people has been collected.
This talk will tell you about the most common health problems experienced by people with intellectual disability living in Europe and Eurasian countries.
Ideas will be shared for improving people's health.

# Symposium 1.8 Drama and Story-Telling Interventions

## Imagining autism: impact of a drama based intervention on the social communicative and imaginative behaviour of children with autism.

J. Beadle-Brown, L. Richardson, D. Wilkinson, N. Shaughnessy, M. Trimingham, J. Leigh, B. Whelton & J. Himmerich

The imagining autism project wanted to find out whether using drama and play could help children with autism. We wanted to know if it helped them to communicate and play better.

22 children took part in the intervention and we collected lots of different information before they had the play sessions and after the sessions.
They played in 5 different scenes in a special tent:
Under the City
In the Forest
Under the Sea
Artic
and Space.

We found that after they had been to play in the tent for 10 sessions, some of the children were better at communicating and at playing and being with others. Almost all the children changed on one type of test but 5 children changed on 4 or more tests. Children also got better at recognizing how people were feeling from photographs of their face.

We will now use this information to find more money to do a much better research project with more children and also a group of children who do not go to play with the drama people.

## Taking part through telling stories: a pilot study of Storysharing®

K. Bunning, M. Johnson & L. Gooch

Stories happen every day of our lives. They help us to talk about our experiences, to make friends and to take part in our community. Some people find it difficult to tell their own stories. We worked with some children and their teachers in a school. The teachers helped the children to tell their stories. We call this the Storysharing® project.

This talk is about what happened when some children in a special school were helped to tell their stories.

We made a film of each child telling their own story with their teacher. We did this at the start of the project and at the end. We looked very carefully at the stories and wrote down what was said. Then we checked how the teachers helped the children and how the children expressed themselves.

We found out that the children learned to tell better stories when their teachers helped them. We think Storysharing® is a good way of helping children with intellectual disability to tell their own stories.

## Community action through personal stories

N. Grove, J. Harwood & C. Moxham

People with severe and profound intellectual disabilities often get left out of public meetings and discussions. They do not get a chance to have their say.

We have tried out some different ways of helping people to get involved in their communities, by telling their stories: in schools, in town planning and political meetings. We found lots of ways that worked well and helped people to join in.

However we also found there were many problems. It was difficult and expensive to get people to the meetings. Some of the ideas are very hard to explain.

We will talk about how we managed these problems and what still needs to be done.

## Imagining Autism: evaluation of a drama based intervention for children with autism – the views of teachers and parents

L. Richardson, J. Beadle-Brown, D. Wilkinson, N. Shaughnessy, M. Trimingham, J. Leigh, R. Whelton & J. Himmerich

# Symposium 1.9 Quality of Life and Quality of Services Around the World

## Disability in the community: a review of the situation for people with intellectual disability in rural Sierra Leone

T. Foday-Musa

## An evaluation of a community living initative in West Dublin

C. Griffiths, F. Sheerin, J. de Vries & P. Keenan

## Perspectives of people with intellectual disabilities and family members to a major reconfiguration of disability support services in Ireland

S. O’ Doherty, S. Craig, M. Kerr, C. Lynch, R. McConkey, A. Staines, M. Tatlow-Golden, M. Walls & C. Linehan

There are people with intellectual disabilities in Ireland who live in institutions. The government recommends: close all institutions support all people with intellectual disabilities to live in the communitygive more individualised support to people with intellectual disabilities. Individualised support helps you have more choices in your life.

We need to understand what people with intellectual disabilities and their families think about this. For example, we need to know: What do people with disabilities think about different types of houses? What does good support mean when you live in the community?

To find out the answers we talked to people with intellectual disabilities and their families. We used 11 focus groups. A focus group is where people come together to talk and answer questions. In total, we talked to 82 people.
Some things we found were:
Most people with intellectual disabilities thought institutions and congregated settings were not good places to live
Family members talked more about staff than places to live.
Experience was very important. It was easier to talk about types of houses you know.

In our presentation, we will talk more about what we found out and what we recommend.

# Crossing boundaries; QOL assessment in 6 countries using the Personal Outcomes Scale (POS)

J.H.M. van Loon, C. Claes, S. Vandevelde & R.L. Schalock

The Personal Outcomes Scale (POS) is used in many countries to assess Quality of Life in persons with intellectual disability. The reason for this international study was to evaluate POS-outcomes across five countries. We compared the typical outcomes of the POS across countries and could study how reliable this instrument is when we use it with many people. The POS was developed for the purpose of assessing quality of life of people with ID. Therefore we looked for specific indicators associated with each of the eight domains of Quality of Life. The POS has been translated in German, Italian, Portuguese, Spanish and Icelandic and administered with 1745 people in these countries. We studied whether there were differences in the results between the countries.We found strong agreements between the countries regarding rights, personal development and self-determination. We also found that the POS can be used in the same way in different countries. And we found that it matters for someone's quality of life where he lives and which employment he has.Studying the POS data from several countries helps us to understand what factors play a role in enhancing quality of life.

## Symposium 2.1 Accessing the Community for People with ID

### Determining the communication accessibility issues of V/Line train travel for people with disabilities

H. Johnson, C. Bigby, D. West, R. O'Halloran, E. Bould & J. Douglas

Aims:

We wanted to find out what problems people with communication disabilities had travelling on trains in Victoria, Australia.

What we did:

We talked to staff and train customers with disabilities about what those difficulties were. They told us what they wanted changed to make life easier for everyone.

Results:

They told us they need communication aids, easy to read printed information and better signage. The staff need training about disability and also about communication.

Ending:

We are going to make some changes on the trains to make communication easier.

## How do people with intellectual disability negotiate the city centre: a report from Sheffield

A. McClimens, E. Sexton & N. Partridge

## Is information enough? Increasing effectiveness of engagement and signposting for people with intellectual disabilities from migrant communities living in England, UK

D. Sallah & O.Kozlowska

## Accessible websites – What is out there?

M. Waight & W. J. Oldreive

The internet gives people lots of different information through web sites. People have written web sites to give information to people with intellectual disabilities. We wanted to see what these web sites were like.

What we did:
We looked on the internet using google to see what kinds of websites there were.

We found 83 web sites.
25 websites were for people with intellectual disabilities. We looked at the 25 websites. We looked to see:
How you could get to the web site
How you could get around the web site and find different pages
How the web site gave you information.

There were 3 ways to give information:
reading,
listening to someone speak or
watching a video.

Were there pictures on the web site to help you understand the information

What we thought:
Some of the websites were good at giving information. There are better ways that web sites can give information. There are better ways to help people find information on the internet.

# Symposium 2.2 Promoting Participation in Research, for People with IDD

## Increasing the participation of people with intellectual and developmental disabilities in health and social care research - lessons from the literature

J. Beadle-Brown, A. Turnpenny, L. Richardson, B. Whelton, S. Ryan, K. Windle, J. Holder & N. Smith

Some people with disabilities and long-term illnesses do not get all the help they need and they often do not take part in research.
We read 83 papers about research to find out:
which groups of people are not included in research
why they are not included
what can be done to help them be included.

We found that the research focused on four main groups who were often excluded from research: People with intellectual disability, older adults with dementia, people with mental health conditions and people from minority ethnic groups.

What stopped people being included in research?
Researchers sometimes think some people cannot take part in research
Sometimes other people would stop information about the research getting to people.
Communication difficulties
Information not being easy to read.
Difficulties getting to where the research was being done.

What helped people take part?
Involving people with disabilities in the research when planning the research.

Researchers with good communication skills and easy to read information

More time

Being able to meet and get to know the researchers before saying yes.

## Promoting participation of people with autism and learning disabilities in research – lessons and experiences from the Living in Fear Project.

C. Guest, R. Marno, A. Finn, L. Richardson, A. Malovic, J. Beadle-Brown & A. Pritchard

We wanted to find out about whether people with intellectual disabilities or autism had bad things happened to them when out and about in the community.

We asked some people with disabilities to help us with the project. Rob, Allan and Kathy chaired our project meetings and gave us feedback about our questions and forms. They helped us prepare the surveys to send out and they helped us let people know about the research. They also helped us to tell other people about the findings of the research.

Allan and Rob will tell you what it was like to participate in the research. Colin will also share the benefits of the having Rob, Allan and Kathy as part of the research team.

There were many more advantages than there were difficulties in involving people in the research.

## Promoting participation of people with intellectual and developmental disabilities in social care research – developing an adapted version of ASCOT for self-report

A. Turnpenny, B. Whelton, L. Richardson, J. Beadle-Brown, J. Caiels, T. Crowther, J. Apps & J. Malley

This project aimed to make the Adult Social Care Outcomes Toolkit (ASCOT) questionnaire easy to understand for people who have intellectual disability. Local authorities and the Government in England use the questionnaire to collect information from people who use social services, for example older people, people with disabilities etc. The questionnaire is used to find out if services help people to live a good life. It is important that people with intellectual disabilities can say what they think about their services. We decided to turn the questionnaire into an easy read form with simple words and pictures. Five people with intellectual disabilities or autism helped us to make changes to the questionnaire. Then we talked about the questionnaire in small groups with people with intellectual disabilities or autism and made some more changes to it. We tried out the questionnaire with 20 people who use services. In this presentation we will talk about the changes we made to the questionnaire. We will also suggest some ideas for other researchers who want to make questionnaires easier to use for people with intellectual disabilities.

# Symposium 2.3 Social Inclusion and People with IDD

## Community-based social inclusion in urban neighbourhoods of adult citizens with intellectual disability and citizens with psychiatric problems; contribution of informal networks

A. Brummel

## The friendships of people with intellectual disability

A. M. Callus

Aims:

For people with intellectual disability to be included in society, it is important that they have equal opportunities. It is also important that society understands their experiences. This paper looks at the experiences of friendship of people with intellectual disability.

Method:

I discussed this topic with a self-advocacy group of people with intellectual disability. I also talked about this topic with different people with intellectual disability who I have worked it.

Results:

In this paper I talk about what these people with intellectual disability said about friendship in the group discussion and individually. I compare this with what other people say about the friendships of people with intellectual disability.

Conclusion:

It is important to understand how people with intellectual disability experience friendship. In this way, they can be included better in society.

# Evaluation of the Factors and Components of Societal Integration of Adults with Congenital Physical Disabilities

O. Hetzroni, R. Peled & O.E. Hetzroni

We wanted to understand how people with physical and developmental disabilities manage to live in the community. So we spoke to many people and learned from them how they managed to live, work and enjoy their life as adults. After we spoke to them we came up with a survey that included seven topics and asked 120 adults with physical and developmental disabilities. We wanted to know what the people felt about themselves, about their work, and about their fun after work.

We found that many of them were happy, but that they did not like their work too much. Some of them felt independent, and had a good relation with their parents, and others felt they didn't. They felt as if the type of work did not bother their ability to be satisfied and able. All the people that answered the survey felt that it was very important and wanted to share their ideas about their work, their life and their activities after work.

## Social inclusion in the neighbourhood from multiple perspectives

T. Overmars-Marx, G.C.F. Thomése & H.P. Meininger

We need to have information about what people with intellectual disabilities need to be part of the neighbourhood. We think that to be part of your neighbourhood it is important to feel at home and be able to participate. For example we asked if is it important to have contact with neighbours or to feel safe. We also wanted to know the view of caregivers and neighbours on what they think is important for people with intellectual disabilities to be part of the neighbourhood. People with intellectual disabilities made pictures of their neighbourhood and told us what was on the picture and why they made this picture. For example there was a picture of a scary place in the neighbourhood where they did not feel safe. We did interviews with professional caregivers and neighbours filled in a questionnaire. People with intellectual disabilities want to feel safe and like to say hello or have a talk with neighbours. Not all of the people with intellectual disabilities feel part of the neighbourhood, they sometimes feel ignored. Neighbours sometimes do not know what to expect from people with intellectual disabilities and find this difficult. Caregivers can help in this situation.

# Symposium 2.5 Social Inclusion, Stigma and Discrimination

## Building robust and supportive communities for people with intellectual disabilities who have experienced trauma

N. Blackman, R. Curen & L. Fodor-Wynne

## Constructing disability: The Effect of NPO Fundraising Campaigns on Attitudes and Donation Behavior towards People with ID

A. Kocman & G. Weber

People with ID should be able to live in our community just like everybody else.

There are many organizations that want to help people with ID to do so.

However, these organizations need money to be able to help.

They get money by collecting donations from people.

They inform people that they can donate by advertisements.

These advertisements often use negative words like “mental retardation".

Also, in these advertisements, people with ID often appear to be unable to look after themselves.

We wanted to know if these advertisements change the way people think about people with ID:
We showed 475 people different advertisements and asked them about their opinion of people with ID.

We also asked them, what they thought people with ID are able to do.

We found out that people expected people with ID to be able to do more difficult activities, when they were called “people with ID" and not “people with mental retardation" in these ads.

People should think about this when creating new advertisements.

# Social participation for older people with Intellectual Disability (ID) living in different residential settings in Ireland: results from wave 2 of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA)

D. McCausland, P. McCallion, R. Carroll & M. McCarron

Doing social activities and having family and friends is important for everybody.
Sometimes it is hard for people with an intellectual disability (ID) to do these things.
We wanted to find out what makes it hard or easy for people:
To do social activities and
To stay in touch with their friends and family.

We asked some people in Ireland what they enjoy doing in their social life.
We asked what family and friends they have, and how much they see them.
We also asked what makes it hard for them to do social activities.

The people we asked were all more than 40 years old. Some lived at home with family or on their own. Others lived in services or in community houses with other people with an ID.

We found out that it is harder for people to do social activities as they get older. It is also harder for people with less ability, and people living in services. It is also harder to keep in touch with family and make friends outside their home.

People living with their family or in the community also find it hard to do social activities and make friends.

# Fighting stigma and discrimination directed at people with ID among the general public

K. Scior, J. Walker, L. Seewooruttun & A. Alam

## Symposium 2.6 Community Living Around the World

### Home and Independence: A study by the Inclusive Research Network

C. Burke, B. Donohoe, M. Dooher, C. Gannon, E. García Iriarte, B. Hogan, R. Hopkins, M. McManus, G. Minogue, L. Phelan, N. Salmon, P. Santry, A. Sexton,

M. Walls & M. Wolfe

In this study, we asked people with intellectual disabilities about their experience of moving to the home they live in.
This study was conducted by the Inclusive Research Network which includes co-researchers with intellectual disabilities, their supporters, and academic researchers.

We used easy-to-read interviews to conduct the study. We interviewed about 30 participants.

We did training with the co-researchers and supporters on topics like:
ethical issuesasking people to take partdoing interviews

We will talk about what the study found out:
people's choices what support they got for planning the move life in their new home.

## South African adults with intellectual disability speak about residential options

J. Mckenzie & C.A. Adnams

## Moving Home: Self-advocates in Nova Scotia and Ireland leaving congregated settings for community living

N. Salmon, E. Burns, C. Callaghan, J. Deegan, C. Keaver & S. Lee

Aims:
To learn how people with intellectual disabilities in Ireland and in Nova Scotia move to the community.

Why?
The stories of self-advocates are key to changing policies so that people with intellectual disabilities are supported to move and live well in the community.

How?
27 stories from self-advocates in Ireland and Nova Scotia were heard. A team of researchers and self-advocates worked together to find links across these stories.

What We Learned:
We need policies that line up with the UN Convention on the Rights of Persons with Disabilities. Even when people have good, long-term relationships with supporters, homes that work well can take a long time to find. Ireland and Nova Scotia are keen to support community living, but Ireland seems to have more housing choices in 2014.

# Institutionalization or de-institutionalization? Directions and issues in the process of assisting the persons with intellectual disabilities in Romania

C. Vasile & L. Duica

# Symposium 2.7 Promoting Staff and Professional Skills

## Understanding professionals’ competence development in working with parents with intellectual disability

E. McHugh, C. Wade, R. Mildon & M. Starke

## The development and evaluation of a training package for community nurses on supporting families with children who have developmental difficulties

R. McConkey, S. Macdonald, M. Sinclair & I. Veljkovik

In many countries community nurses support families who have babies with developmental disabilities.

However these services are not well developed in countries that belonged to the former Yugoslavia.

We first found out what training they needed.

We planned a training package that aimed to change the attitudes of nurses, increase their understanding and help them to acquire new skills.

We will describe the content of the nine modules and the teaching methods used.

Around 20 managers have been trained to use the package in their services.

This approach is a good way of providing inservice training for community personnel.

## Professionals’ experiences of conducting research interviews with parents who have children with disabilities

M. Starke & H. Nowak

## Planning for the future for family carers of adults with intellectual disabilities (ID): training-the-trainers: a pilot study

A. Thompson & L. Taggart

# Symposium 3.1: Intervention Projects with Children and Adults with ID

## The development of an intervention to promote the capacity to wait in children with intellectual disability

L. Gilmore, M. Cuskelly, S. Glenn, A. Jobling & V. Martin

## Family-Centered approach in Early Intervention in Spain: opportunities and challenges

J.M. Mas, A. Balcells, C. Giné, M. Gracia, A. González del Yerro, M.J. Galván & D. Simó

Some early intervention centers in Spain are trying to change the way they work. They are focusing their work on the family and their capacities. We want to know the challenges that the professionals are facing in this process of change.

We worked with professionals and families of different early intervention centers of Spain. We had 11 teams. Each team was formed by a professional, a family and one of us. We analysed practices of the professionals using different questionnaires and interviews.

We found out that professionals and families were facing different challenges during this process. In particularly, they found difficult to change the model where the expert is the professional and work together with the family.

We suggest different actions to address these difficulties:
(1) training for the professionals of early intervention centers,
(2) focus the intervention on the daily routines of the families, and
(3) work together with professionals to identify best practices to work with families.

## Experiences from a longitudinal intervention project in Sweden

B. Nyqvist Cech

## Symposium 3.1: Intervention Projects with Children and Adults with ID

### The role of self-advocacy groups in challenging traditionally exclusive patterns and negative attitudes towards persons with ID in the community

M. Birtha

Aims:Persons with disabilities and their organizations played an important role in drafting the UN Convention. The UN Convention includes all the rights of disabled people. Persons with intellectual disabilities are still marginalized within the disability community. It means that their voice is not heard. Persons with intellectual disabilities often do not participate in the community.

The presentation will discuss the challenges that persons with intellectual disabilities have to face. The presentation will show positive practices on how to be better involved in the community.

Method: There were research trips organized in Zambia, New Zealand and in European countries. People with intellectual disabilities told what they think about their involvement. They explained what is necessary to change in the future.

Results: People First New Zealand is a good example to be involved in a meaningful way.The National Platform of Self-Advocates Ireland is a new independent organization of self-advocates. The Platform wants to be more independent and receive the right form of support.

Conclusions: We need to change many things to ensure people with intellectual disabilities can participate. Participation should be meaningful. If persons with intellectual disabilities participate in the community, it will be a better society for all.

## Quality of life of people with intellectual disability in Israel- Participatory Evaluation approach

D. Roth & B. Hozmi

A good quality of life should be provided by services to People with ID. The view of the People with ID was studied as well as the views of staff. The purpose of the evaluation was to identify how the quality of life can be improved.

People with ID were full partners with the researchers. They developed part of the evaluation measures, analyzed, discussed, concluded and made recommendations.

Differences were found between the consumers and the staffs' perspectives of quality of life: Control and autonomy were the least satisfactory items rated by the PWID. Social belonging, productivity and general life satisfaction ranked highly. Differences between what staff viewed as important to them and what they thought was important to the PWID were found. There were great differences what staff thought PWID will respond and what PWID responded on QOL domains Evaluation relating to PWID should be conducted by inclusive methods.

It gives insights and information which can be missed in traditional evaluation methods. In addition it empowers the participants, involves and gives them responsibilities in problem resolutions.

## Including adults with ID in actions to raise disability awareness among public service employees. People with ID coch public service employees-a best practice example

M. Schock, B. Gary, M. Reding & B. Stencel

People with intellectual disabilities want to use busses and trains. Sometimes, they need more guidance than other passengers. It is important to teach bus drivers and train conductors how to provide such guidance appropriately.

For the last 3 years people with intellectual disabilities have helped to instruct bus drivers and train conductors. 2 support workers assisted them.
For example they told the bus drivers and the train conductors about:

- How to treat people with intellectual disabilities respectfully.
- Bad examples
- Good examples

People with intellectual disabilities prepared themselves for the meetings with bus drivers and train conductors. They met every week to discuss what they want to say and how they want to say it.

We found out:

- Pepole with intellectual diabilities got more confident asking for help.
- Bus drivers and train conductors were eager to learn how to assist people with special needs. They listened carefully and asked a lot of questions.

## Self-advocacy and resistance in Sweden

M. Tideman, T. Mineur & O. Mallander

## Symposium 3.3: Inclusive Research with Children and Adults with ID

### Having their say! Children and young people with intellectual disabilities who live in public care in Northern Ireland

S. Dowling, B. Kelly & K. Winter

### Building a community of inclusive practice through co-researching

P. O'Brien, R. McConkey & E. Garcia Iriarte

# Inclusion in research on employment: The voices of adults with Intellectual Disability.

J. Pahl, C. Tod & S.B. Karrim

People with Down syndrome should be asked what they think and feel. This talk looks at people with Down syndrome being part of research studies. We spoke to five people with Down syndrome, their bosses and their family. It is very important that the person wanting to know about Down syndrome asks the person with Down syndrome if they want to answer the questions in the research study. They should sign a letter to say they are happy to answer questions. If they cannot read or write then their family can sign for them after explaining. This letter must be easy to understand. Family can help to plan the day and place where the questions can be asked. The questions must be easy to understand and should not take a long time. The person with Down syndrome's name should not be told to anyone.  It is important for the person asking the questions to say the questions in a way that a person with Intellectual Disability will understand. People with Down syndrome are the best people to say what they find hard and what they do not like. Other people can learn from what they say.

# Inclusive research with people with intellectual disability: the Question-Aires way

R.W. Williams, S. Harris, D. Lomas, M. Perkin, G. Gallagher, S. Nash, J. Huws, A. Green, F. Waddington & J. Payne

People with intellectual disability can contribute to research in healthcare in a positive way. This talk is about how the Question - Aires Research Group includes people with and without intellectual disability as researchers. The people with intellectual disability are involved in:

- reading about research already available,
- deciding what research questions are important to them,
- thinking about what questions to ask, and who could answer the questions,
- presenting information about their research and getting people interested in taking part,
- asking the research questions, and
- making sense of peoples answers.

The Question-Aires research group have faced many difficult tasks. But by working together people with and without intellectual disability have learnt:

- from each other,
- the importance of taking time to make decisions
- that research can be presented in easy language, and
- that being a researcher can be a paid job.

The Question-Aires are a new research group that shows that people with and without intellectual disability can benefit from doing research together.

## Symposium 3.4: Technology and Innovation in Community Services

### Aided AAC service provision: Focusig on South Korea's Assistive Technology Center Pilot Project 2009-2012

M. Koh

There is an increasingly interest in Alternative and augmentative communication (AAC) service for those people with intellectual disabilities in South Korea. So, I need information about:
What kind of the AAC service is provided for a person with intellectual disability?
How is the AAC service provided?

I interviewed occupational therapists, assistive technology professionals (ATP), social workers who have worked for people with intellectual disability.

I found out that:
service providers should understand users as unique individuals;
service providers should provide an assistive technology which meet users’ need;
service providers should help users and relevant people to use the AAC well;
service providers should find money to buy the assistive devices.

## Using conversations to bring about change within the service system: a blueprint for redesign and transformation

P.M. O’Brien, S.R.C. Arnold, D. Espiner, J. McCredie, A. Robinson, E.L. Doukakis & C.L. Gore

## Evaluation of the impact of a service-learning project on students with intellectual disabilities.

J. Teng,C. Kwek & B. Lee

We sought to find out if students with intellectual disabilities can learn about community service, teamwork and responsibility while doing community service. We came up with community service project with 5 hour-long drumming practice sessions for 6 students. The students performed to a group of elderly after all the practices.

At the end of the project, we interviewed the students, asked the teachers to fill up the feedback forms and asked strangers to rate the students at the start of the first session and at the end of the last session of the project.

We found out that the students, teachers and strangers gave us similar information. All students showed an improvement in teamwork, self-confidence and responsibility during the practice sessions as well as in other lessons in school.

We also found out that they learned other social skills such as helping others and managing anxiety.

Hence, we suggest that this kind of participation is a good way for students with intellectual disabilities to learn social and life skills.

## Use of technology by adults with intellectual disability

C. Tod, J. Pahl & S.B. Karrim

Lots of people use mobile phones, iPads and computers. This talk looks at how people with Down syndrome like to use these too.

Five people with Down syndrome, their bosses and their family were asked what they do with mobile phones, iPads and computers at work. The people with Down syndrome taught themselves how to use mobile phones and liked to use them to talk to friends.

They wanted mobile phones because many other people had them. The people with Down syndrome used their mobile phones to make calls, send messages, take photos, play music and games and use the internet to talk to others.

They knew that they should not use their phones at work. Some of the people with Down syndrome started using a mobile phone and then learnt to use other things like iPads and computers.

Some of the people with Down syndrome used mobile phones, iPads and computers even though they could not read and write very well.

People with Down syndrome like to use mobile phones, iPads and computers and these can help to make their reading and writing skills better, to feel better about themselves and can help them at work.

## Symposium 3.5: Quality of Life

### Psychometric properties of personal outcome scale children version

L. Croce, M. Lombardi, S. Vandevelde & C. Claes

### Measuring Quality of Life

C. Terrill

AIMS: This session will look at quality of life as defined by the person with intellectual disabilities have

METHODS: There are 21 Personal Outcome Measures. Individuals are interviewed to measure outcomes present in their lives. 8486 people were interviewed in the USA.

RESULTS: There has been an increase in the outcome “Individuals exercise rights”, but the average of all years indicates that only 51% of respondents identify achieving this outcome. There was a drop in the outcome “Individuals experience continuity and security in services”. The trending data offers insights into the causes for such changes. The data shows changes in service quality and outcomes.

CONCLUSION: Interviews findings reveal that safety, security and health are supported in USA organizations. Exercising meaningful choice in important life decisions remains a challenge for most people. Community integration and enhanced social roles are least likely to be present in people’s lives.

## Improving Quality of Life, Fulfilling Rights. The Use of the POS-A in Support Plans for People with ID

J.H.M. van Loon, C. Claes & R.L. Schalock

It is important that the UN Convention on the Rights of People with Disabilities is followed. Therefore it is good to have instruments that can be used to measure how the situation with these rights is with persons. There is a close relationship between the eight quality of life domains and the UN Convention Articles. The purpose of this presentation is to demonstrate how an instrument to assess quality of life (The Personal Outcomes Scale-Adult (POS-A), can be used to assess the status of the rights of the Conveention.

The POS-A was administered to a group of 150 individuals with ID in a large community-based program in the Netherlands.

The POS-A provides information to enhance an individual’s well-being. This information can be used in developing Support Plans that enhance the rights elaborated on in the UN Convention. Specific examples will be presented.

## Community Participation and social interactions of persons placed in the community based residential services. Developing and testing the Community Participation and Quality of Social Interactions Survey

M. Zelić

Aim: We need to have information about community involvement and relationships with others, for people with intellectual disabilities who moved from institutions into community. For example, answers on further questions: Are people with intellectual disabilities included in the community?
Have people with intellectual disabilities relationships with others?
With whom and how often?

Method: We applied a survey to find out how people with intellectual disabilities are included in the community and have they relationship with other people. This survey is called the "Community Participation and Quality of Social Interactions Survey". It has 20 questions. We asked these questions to supporting staff and service coordinators who knew each person with intellectual disability. This survey was filed out for 62 people with intellectual disabilities who have been moved from institutions in to the community settings in the Republic of Croatia.

Results: People's age, duration of living in the institution and the level of intellectual disability had the greatest influence on community involvement and relationships with others.

Conclusion: The survey proved to be a good way to obtain information about the involvement in the community and relationships with others, for people with intellectual disabilities.

# Symposium 3.6: active support & positive behaviour support training

## The relationship between communication and quality of person centred active support

T. Iacono, C. Bigby, E. Bould & J. Beadle-Brown

## Predictive role of casual attribution in coping activity of mild intellectually disabled students in social daily hassles

P. Kurtek

## An evaluation of positive behaviour support training

A. MacDonald & P. McGill

## Symposium 3.7: Staff Support for People with IDD

### The nature, extent and role of practice leadership for staff teams supporting people with intellectual disability

C. Bigby, J. Beadle-Brown & E. Bould

### Support staff views of the futures of adults with intellectual disability

M. Cuskelly, K.B. Moni, M. McMahon & J. Lloyd

# Interactions between people with intellectual disabilities and staff in residential housing

M. Røgeskov

It is important to know how people with intellectual disabilities (ID) and staff are together in residential settings. It is also important to know how both parties experience being together and what makes a success.

This study is about: What makes people with ID and staff happy and gives them energy when they are together?How can common activities make people with ID and staff more equal? These two questions are studied by doing observations in two residential settings. I also interviewed people with ID and staff about their experiences. The observations and interviews took place in two residential settings. In these settings people with mild to moderate ID lived.

This is what I found in the study. People with ID and staff are happy when they do a common activity together. People with ID and staff receive energy out of being together when they do an activity together. Doing an activity together makes it possible for people with ID and staff to participate equally.

## The focus of direct support professionals on (reversed) integration

E. Venema, C. Vlaskamp & S. Otten

Aim: In the Netherlands there are three types of living for people with an intellectual disability(ID):
Residential facility, regular integration setting and a setting of reversed integration. Reversed integration means that people without ID move to the ground of a residential facility were people with ID are already living. In the process of integration of the people with ID the direct support professionals play an important role. It is unknown what influences DSPs in their focus on integration and if there are differences in results between DSPs working at the three different settings.

Methods: A questionnaire was taken from 927 DSPs working in three different settings. The questionnaire consists of 52 statements about five different possible influences.

Results: Four influences (attitude, competences, identity and meta-evaluations) have influence on the DSPs' focus on integration. There were some differences found between the settings.

Conclusions: The results will be displayed in a model. This model can be used to stimulate DSPs in their work towards integration. Differences between settings can be explained by the severity of the disability of people with ID and the degree of psychiatric and/or behavior problems.

# Symposium 3.8: Support needs and Support Planning

## Support needs predict funding need better than adaptive behaviour

S.R.C. Arnold, V.C. Riches & R.J. Stancliffe

## Individual support planning: bridging the gap between policy and practice

M. Herps, W.H.E. Buntinx & L.M.G. Curfs

## This Is How I Do!: a person-centred self-assessment tool of describing support needs in life

A. Rajalahti, K. Ristikartano, M. Kosola, M. Ahlstén & M. Koski

## Professional Participation Planning through Counselling Centres in the Rhineland/Germany: requirements, forms of implementation and perspectives

E. Weber, D.C. Knoess & S. Lavorano

Aims: The presentation is about counselling and Participation Planning in Germany. This is often done by service providers. In a project new ways of counselling were tested. A study about this project was made. The study about ways of counselling will be presented. The aim of the study was to describe good Participation Planning. Another aim was to show what counsellors need to make good counselling.

Methods: In the study a lot of persons were asked about Participation Planning. Some got questionnaires. Some were interviewed. These persons were interviewed: Service providers, persons with disabilities, funding agencies, counsellors. They were asked if the project was good. They were also asked what should be changed in counselling processes. The researchers looked what people said in the questionnaires and interviews. For this they used a method. This method is called grounded theory.

Results: One result of the study is that counselling can be done by different groups. Counselling should not be done only by service providers.

Conclusions: It is possible to describe good Participation Planning. Counselling in Participation Planning is very important. The persons who work as counsellors need more information. Persons with disabilities must participate in this process.

## Symposium 3.9: Family Carers and Support for Families

### The relationship between autism services and mothers' wellbeing

S. Hodgetts, D. McConnell, L. Zwaigenbaum & D. Nicholas

### 'A place where it's ok to have some peculiar things at home': siblings' definition of sibling support

T. Moyson

### Experienced and needed parental support in non-western immigrant families with a child with mild intellectual disabilities (MID) in the Netherlands

P. Swennenhuis

### Mutual support: an exploration of the role of adults with ID caring for their older family carers

M. Truesdale-Kennedy, L. Taggart, A. Ryan, R. McConkey & G. Adamson

## Subjective wellbeing and young people with intellectual disabilities: Does attending a peer populated sports groups improve wellbeing.

Ch. Garrod & P. Oakes

We wanted to find out if kids with learning problems playing sports with other kids with learning problems amde them feel happier.

What we did: We asked 8 kids and their parents to complete a form with qauestions about their lives. We then asked them some questions about tyhe sports group and their lives. Sometimes we used pictures and we also asked the kids to draw pictures to help us all know what playing in the sports group meant to them.

What we found out: The kids and their parents said that they liked going to the sports group as it helped them to make friends, feel happy, do fun stuff that they were good at and get fitter.

What we did next: We thought that the sports group was a good idea as it helped kids with learning problems feel happier. We also felt that we could ask kids about how they felt going to other groups.

What we found out has helped the group get more money so that it can keep going.

# Determinants of Health Care Service Utilization in People with Developmental Disabilities : An application of the Gelberg-Andersen Behavioral Model for Vulnerable Populations

S. E. Cho

This study talks about what kinds of people with developmental disabilities use more health care service. This study found that among the people with developmental disabilities, those who have the below characteristics use more health care service:

- they think they get enough help from family and others
- they need more help in doing daily living activities
- they have more than 1 disability
- they have adulthood health problems
- they have higher health care service needs.

From these results, this study suggests: Everyone with developmental disabilities has different situation. So, health care policy should be established according to his/her situation. The study shows that people with developmental disabilities who think that they need health care service use more service than who do not. But, usually, they do not know about the services. So, information on the services and the guidelines for how to use the services should be provided.

## Spirituality and people with Intellectual Disability (ID): Comparing the significance of faith and spirituality in faith and non-faith based care services.

P.N. Sango, R. Forrester-Jones & M. Calnan

Introduction: There are little studies on the spiritual lives of people with learning disabilities. This study looks at one service where the care is based on faith and spiritual ways of working. Another service is not based on faith. We want to see if the two services are different. We want to see if both services help people with learning disabilities to practice their faith. We also want to find out how important spirituality and faith care are for the life of people with learning disability.

Methods: Staff and people who lived in both services took part in the study. They were asked questions about their life, their faith and people they know. Staff were asked what they thought about spirituality. Six months were spent helping and taking part in the activities and making notes.

Findings: People with learning disability enjoyed going to church, praying and singing. Staff said that all the work they had to do in the homes; low staff and low transport sometimes made it hard to take people to church.

Conclusion: Learning disability care homes need to support people with learning disability to take part in faith activities like going to church, praying and singing.

## An environmental scan of community-based primary healthcare in relation to adults with IDD in four Canadian provinces of Manitoba, Ontario, Nova Scotia and Québec

S. Shooshtari, V. Cobigo, J. Lecomte & H. Ouellette-Kuntz

## Symposium 3.11: Supporting Families

### Perinatal Hospice: Supporting families with a dying baby during pregnancy and early life

H. H. Goll

During pregnancy, some parents come to know that their baby has a serious disability. The baby will die before or shortly after birth.  Many parents decide to continue pregnancy. They experience togetherness with their child using communication or preserving memories (pictures, footprints). The parents make a plan for birth and death of the baby.  Professionals support the parents and the dying child. This process in early life is called Perinatal Hospice Support.

## Caring for adults with intellectual disability in South Africa: family members' perspectives

J. Mckenzie, R. McConkey & C.A. Adnams

## Parents' perception of received support during their youth's transition period and their perception of their youth's future

H. Nowak, M. Broberg & M. Starke

## The Magenta Project: effectiveness of an intervention on managerial skills for parents with a young child with disabilities

N. Seghers & B. Maes

# Symposium 3.12: Support and Citizenship

## Magic2: An innovative informatics tool to support a multidisciplinary approach to child/family and person with Developmental Disabilities in a lifespan perspective

G. Albertini, E. Chiodi & C. Condoluci

## Looking good: Multiple meanings for the body image of women with intellectual disability

J. Conder, B. Mirfin-Veitch & M. Crowe

How women see their body and what they do to look good will affect opportunities they have in the community.

We talked to 25 women with intellectual disability about their body. This speech is about what they told us.

Most of the women were happy with their body. The things they did to look good were about being clean and tidy. Unlike most women many did not see any importance in wearing make-up or making themselves attractive to other people.

Having an attractive appearance can be important to participating in the community. Assisting women with intellectual disability to think about how they look to others might give them more opportunity to take part in community life alongside other adult women.

## A Study about the Experiences and Support for Couples with Intellectual Disabilities in Japan.

E. T. Nagaoka

There are far fewer couples with intellectual disabilities than those without in the same generation in Japan. All the same, many disabled people want to marry. I researched the experiences of these couples and tried to find out how they were supported.

I interviewed 38 couples and used Life Structure Theory and Resources of Livelihood for my study. According to Life Structure Theory I divided their lives in four parts; 'before marriage', 'preparing marriage', 'after marriage', and 'in the future'. As Resources of Livelihood, I used 6 resources; 'house', 'labour', 'money', 'time', 'information', and 'identity'.

As a result of the survey, I found out the following: The marriage of some couples was opposed by relatives. The reasons were rooted in Japanese culture.Some of the couple were parents who loved their children and tried to be good parents the same as the non-disabled. The support available depended on the needs of the couples and the availability from support organizations.

In conclusion, I recommend that we need more opportunities to share the experienves of couples and supporters to create better support systems.

## Symposium 3.13: Community Integration and Accessible Information

### Knowledge that counts: the struggle between professional and performative perspectives on encounters between neighbours with and without ID

G.F. Bos, T.A. Abma, H.P. Meininger & F.A. Renders

Some care organizations in the Netherlands sold a big part of their ground for houses for people without intellectual disabilities. They hope that people with and without intellectual disabilities will be happy to meet each other in these new neighbourhoods.We wanted to know what happens between neighbours with and without intellectual disabilities. For example: What happens when they meet each other? What do caregivers do when neighbours with and without intellectual disabilities meet each other?

We spoke with many people about the new neighbourhoods: people with intellectual disabilities, family members of people with intellectual disabilities, new neighbours, caregivers, managers.

The speech is about the different ways these people talk about living together in the neighbourhood. We found that many caregivers think that something bad will happen when people with and without intellectual disabilities meet. We also found that many new neighbours think that caregivers know best how to react towards people with intellectual disabilities. As a result, there is little neighbourhood contact. We suggest that people with intellectual disabilities, caregivers and new neighbours should talk together about what they wish and expect in the new neighbourhood.

## Organized solidarity: contact between people with intellectual and mental disabilities and neighbours

F. Bredewold, E.H. Tonkens & M.J. Trappenburg

## Supporting decision making through the implementation of health-related accessible information

C. Mander

Without easy information, it can be difficult for people with intellectual disabilities to make decisions about their healthcare. I looked at what happened when easy health information was used. I recorded four different sessions between a community nurse and one of their clients with intellectual disability. I was interested in what they said and what they did when using easy information. A lot of interesting things happened in the sessions: When looking at the easy information, the nurse and their client moved closer together, this helped them think about the same information at the same time. The nurse sometimes talked about other health topics to help their client understand. Sometimes, the nurses had two jobs to do and this was difficult. They wanted to help their client make their own choices and they wanted them to have the healthcare that they thought was best for them. Watching the sessions helped me to realise that there are many different stages to using easy information. You can have a really good resource, but it’s what you do with it that really counts.

## If "Good information is the basis for genuine shared decision making€� DoH 2010 – why aren't we doing it?

M. Waight & W. J. Oldreive

The UK government says that people with intellectual disabilities should have information that they can understand. They say that people with intellectual disabilities have a right to have information they can understand. The government has written laws that say this must happen. The government has written books about how this much happen. Other people like Mencap and the European Union have written about how to make information easy for people with intellectual disabilities to understand.

We looked at all what they said. We looked at some of the guidelines about information. We looked at easy read and at web sites.

Lots of people make easy read information but no one checks how good it is. Everyone is given the same information. People with intellectual disabilities can find information hard to understand. We have been looking at ways to make this easier.

We think that people should be helped to understand information. We think that people should be given in a way that is right for them. We have thought of a way to make sure that the information people are given is right for them.

# Symposium 3.14: Parents with Intellectual Disability

## Exploring the social worlds of children of mothers with intellectual disability

S. Collings, G. Llewellyn & R. Grace

## Parents on the outside –A pilot study of a support group for parents with cognitive limitations who have lost the care of their children

G. Janeslätt, K. Jöreskog, L. Springer & P. Adolfsson

Aims: This small study wanted to see if a group support called “Parents on the outside" was good for mothers with cognitive limitations who have lost the care of their children. Did the support group help the mothers to feel better in parenting when they met their children? The study also tried if two different self-rating forms were useful for parents with intellectual disabilities.

Method: Eleven mothers participated in the support groups. To find out if the group helped them, four mothers completed one self-rating questionnaire and the other seven completed Parenting Sense of Competence scale (PSOC) in the first and the last meeting. One group was interviewed.

Results: The mothers said that that being in the group with the other mothers helped them with their 'new’ parenting role.The mothers felt better and thought they had become better parents.

Conclusion: “Parents on the outside" was good for these mothers. More research is needed to know if it is also good for other parents with cognitive limitations who have children in foster homes. We need to do more work on finding good ways to interview the participants as well as to help them to complete a questionnaire about parenting.

## Parents’ perceptions of taking part in Parenting Young Children – a parenting program for parents with intellectual disability

M. Starke, C. Wade & R. Mildon

## Theme: Participation Over the Lifespan

## Symposium 1.1. Dementia & Intellectual Disabilities

### Sharing the diagnosis of dementia: breaking bad news to people with intellectual disabilities

I. Tuffrey-Wijne & K. Watchman

## Why's my friend doing that? Raising awareness of dementia in adults with ID using computers.

M. Waight & W. J. Oldreive

People with Intellectual disabilities can have dementia. The people who live with them can find this very confusing.It can be very hard to see someone you like become ill.

What we did: We worked with 3 people who share a house with a man with dementia. No one at the house could read. We used a computer to tell them about dementia. We made sure that they could understand what was happening.

What happened: The 3 people were able to understand why their friend needed more help. One person asked questions about what was happening. The staff were able to talk to her about her friend’s dementia. The other 2 people were not very bothered about the information.

What we learnt: People need information to be right for them. People need to help make information right for them.

## Strategies to reduce the marginalisation of people with intellectual disabilities and dementia

K. Watchman

People with intellectual disabilities are often not included in their local communities, in health checks, or in other aspects of society such as work. After the diagnosis of an illness, such as dementia, people with intellectual disabilities are likely to be excluded even more. My research looked for reasons why this might happen.

Method: Three people with an intellectual disability and dementia were visited every month for three years. I wrote about what I saw happening in their lives and looked for things that were the same and that were different for them.

Results: I found that the three people who took part had not been told that they had dementia, they did not know that they were ill. Staff and family did know and this affected how people with intellectual disabilities were treated and spoken to.

Conclusion: My research suggests that there is not enough sharing of information between services that help people with intellectual disability and services that help people with dementia. We need to find out more about how people can live well when they have dementia and to learn about how best to talk to people about dementia.

## Screening for Dementia: A Feasibility Study of the NTG-EDSD in German-language

E.L. Zeilinger, C. G€artner, S. Maxian & G. Weber

Aims: Assessing dementia in persons with intellectual disability (ID) is difficult. Recently, a new instrument for assessing dementia in persons with ID was developed in the USA, called the NTG-EDSD. The two goals of this study were to translate the instrument to German-language and to examine the feasibility of the instrument.

Method: First, the NTG-EDSD was translated into German in a stepwise approach by five experts in ID, dementia, clinical practice or research. For the feasibility study 221 professional carers for ageing persons with ID in Austria and Germany completed the NTG-EDSD and an additional questionnaire assessing its feasibility and utility.

Results: Overall feasibility evaluations showed good results. Reported problems and suggestions for improving and/or amending the NTG-EDSD were collected and are discussed with respect to the practicality of the instrument.

Conclusion: Due to the differing premorbid cognitive-level of persons with ID, a baseline assessment followed by periodic re-assessments is recommended when screening for dementia. The NTG-EDSD could become a valuable tool for a thorough dementia screening procedure, and consequently help in delivering adequate interventions and care.

## Symposium 1.2. People with Profound Intellectual and Multiple Disabilities

### Story garden: an exploratory research on the story experiences and experiencing with stories for persons with PIMD

N.-C. Chen & Y.-Z. Wang

### Generation and elimination of fear: dialogue between dentists and persons with PIMD

N.-C. Chen, S.-T. Huang, Y.-F. Su & Y.-Z. Wang

## Evaluating the effect of person characteristics on joint attention behaviors of people with profound intellectual and multiple disabilities

H. Neerinckx & B. Maes

Joint attention' may happen when two persons are in interaction with each other. It means that these two people have attention for each other as well as for an object that is included in their interaction. People use attention behaviours such as looking, reaching, talking, ... . With these behaviours they try to direct the attention of the other or to follow the attention of the other. We wanted to know which personal characteristics of persons with complex support needs influence these attention behaviours. Therefore, we videotaped 42 persons with complex support needs when they were together with a researcher. First, we looked at these recordings and noted which behaviour was shown by the person with complex support needs. Second, we evaluated their developmental age, their motor problems, their sensory problems and their temperament. The results will be presented during the congress. We saw that the motor abilities influence the way in which persons with complex support needs direct the attention of other persons. Also their level of perseverance influences their attention behaviours. Persons with a higher developmental age show attention behaviours of a higher level.

## Symposium 1.3. Ageing and Intellectual Disabilites

### Perspectives on ageing by people with intellectual disabilities and their family carers in Belgium

A. De Winter

### What do people with intellectual disabilities and their family carers say about ageing?

R. Raghavan

### Ageing **and intellectual disability: a European perspective**

R. Raghavan & A. Brandstatter

# Symposium 1.4. People with Profound and Multiple Disabilities

## Correlates of physical and mental health of family carers of people with profound intellectual and multiple disabilities (PIMD)

D. Chadwick

What we wanted to find out:
We wanted to find out what worries and supports families of people with intellectual disabilities and other health problems made them feel healthy or not healthy.

What we did:
With the help of some family carers, we made a survey to ask families about their concerns and supports in life and about their health. This talk will be about what families told us when they filled in this survey. 555 family carers filled in the survey. In our speech we will just be talking about 96 of these family carers who supported people with intellectual disabilities who also had other health problems.

What we found out:
The families had concerns about not having enough help in the home and respite. They also wanted more therapy services and easy to understand information. Some of the things that made families feel good or bad included the money, support and services they had and used.

## Do they agree? How parents and professionals value the support provided to persons with profound intellectual and multiple disabilities

S.L.G. Jansen

## The impact of rearing a child with PIMD: research into time use of parents

J. Luijkx, A.A.J.van der Putten & C. Vlaskamp

A child with a profound intellectual and multiple disability (PIMD) needs help from others during all moments of the day. That is why parents have to help them with almost everything. So they play a very important role in the lives of their children. In this study we look very precisely at the way parents of children with PIMD use their time. For example, we need information about:
How much time do parents need for helping their child with PIMD?
How much time do parents use for working?
How much time do parents use for leisure?

We came up with a smartphone application to find out how parents use their time. Almost 35 parents (both fathers and mothers) of children with PIMD in the Netherlands kept track of everything they were doing for seven days. The presentation will be about the results of this smartphone application.

## Symposium 1.5 Quality of Life and Services

### Engineering change in the culture and practices of a service for people with intellectual disability.

C. Griffiths, P. Keenan, D. McCausland, G. Hynes, M. McCarron & P. McCallion

Engineering change in the culture and practices of a service for people with intellectual disability. Or Improving lives for people with intellectual disability who live in large residential services. We tried to help a big service that has many people with intellectual disability living in it become more interested in each person. We held 114 meetings with 22 people who lived in the service as well as their families and the staff who looked after them. The meetings took place over 10 months. We found that that people wanted to do more things in the community especially if family members could help them to do that. We also found that changing the way staff work was difficult but needed to be done. We discovered a way of helping a small part of a big service to change so that it became more person-centred and better able to help people with intellectual disability to live the lives they wanted.

## Evaluating quality of life and subjective wellbeing in children with PIMD

B. Maes & P. Vos

## Quality of life in families with children with a disability

J. Nicklas-Faust

## The practical use of video interaction guidance to improve communication, interactions and knowledge transfer between people with PIMD, staff and family members

M. Phillip

## Symposium 1.6. Longitudinal and Population-Based Studies in IDD

### The Mental Health of Parents of 11 Year Old Children with and without Intellectual and Developmental Disabilities

E. Emerson, C. Hatton, J. Robertson, S. Baines, V. Totsika & R.P. Hastings

The parents of some children with intellectual disabilities are unhappy.

We want to know why.

We are looking at the parents of children in the UK from a very early age until they are 11.

We are still working on this project. We will tell you what we found at the conference.

### Financial Burden of Families Raising Children with IDD in the US

S. L. Parish & E. Son

Not much is known about how much it costs to raise children with intellectual and developmental disabilities in the USA. We wanted to learn about these costs. We looked at a national survey of 7951 children with intellectual and developmental disabilities from across the USA. We found that it is expensive for families to pay for all the things their children with intellectual and developmental disabilities need. Parents had problems caused by their child's health. Stronger policies, including cash assistance and better health insurance are urgently needed in the USA.

### Marriage, separation and after: a longitudinal study of families who have children with disabilities in Norway

J. Tøssebro & C. Wendelborg

### Comparing carers of people with an intellectual disability, mental health problems, and dementia: sociodemographic profile and psychological adjustment

V. Totsika, R.P. Hastings, E. Emerson & D. Vagenas

We would like to understand better who are the people who care for people with an intellectual disability in their homes. In England, a survey found out people who live in their own homes and care for someone. They are usually family members. We will look at this information to understand how old carers are, whether they are men or women, and if they have enough money. Carers were asked how was their health, whether they were happy, and how is their life now. We will describe what carers of people with an intellectual disability have said. We will compare them to carers of other people such as people with dementia and mental health problems.

# Symposium 1.7. Behaviour of Children with IDD and the Impact on Parents

## A content validation of the family impact questionnaire for Swedish families rearing children with intellectual and developmental disabilities

M. Broberg & V. Cederblad

# Parental causal attributions for child misbehaviour and their relationship with parenting strategies: A comparison between parents of children with intellectual disabilities and typically developing children

M. Jacobs, L. Woolfson & S. Hunter

Children with intellectual disabilities (ID) show more difficult behaviour than children without ID. Parents of children with ID also experience more stress than parents of children without ID. To support these parents, we need more information on how parents of children with ID think about their child's behaviour. Fifty-one parents of children with ID and 69 parents of children without ID participated.

By using a questionnaire, we asked them how they thought about their child's difficult behaviour. For example, we asked them

- how much they thought the child or the parent could control difficult behaviour?
- how much they thought the child or the parent was responsible for difficult behaviour?

We also asked parents how they reacted when their child misbehaved.

We found that parents of children with ID were better at dealing with their child's misbehaviour when they thought the child could not control the behaviour. They were also better at dealing with their child's misbehaviour when they viewed themselves as responsible for it. We did not find this for parents of children without ID. This means that behaviour support should be adapted to the specific views and needs of parents of children with ID.

## Use of Harsh Parenting Practices in Parents of Children with Disabilities

D. Norlin, U. Axberg & M. Broberg

Are children with disability treated more harshly by their parents than other children?
We need to know if parents yell at, slap or hit their child more when the child has a disability. We also need to know if the risk for that is higher in some families:
Is the risk higher when the family is poor?
Is the risk higher when the child has bad behaviour?

We asked questions to parents about how they treated their child. Some were parents of children with disability, and some were parents of children without disability.

In our study, children with disability were not treated more harshly than other children. Among children with disability, those who had bad behaviour were treated more harshly than other children.

We think that parents who have a child with disability need someone to talk to about how to raise their child. This is especially important if the child has bad behaviour.

## The relationship between challenging behaviour, cognitions and stress in mothers of individuals with intellectual disabilities

J. Rose, L. Nelson, N. Phillips & R. Hardiman

# Symposium 1.8 People with Profound Intellectual and Multiple Disabilities

## Effects of the high quality communication intervention in people with dual sensory and intellectual disabilities

S. Damen, M.J. Janssen & C. Schuengel

## Social networks of persons with (severe) profound intellectual and multiple disabilities: the current situation of the professional support in personal files

A. Kamstra, A.A.J. van der Putten & C. Vlaskamp

Having family and friends is very important for everyone. Also for people with severe or profound and multiple disabilities (PIMD). People with PIMD are not able to decide for themselves when they want to see someone, because they are not able to talk. If a person with PIMD is not living at home anymore, the direct support person should help. We need more information about what the direct support person thinks about contact with friends and family. Every person with PIMD has a personal file, written by the direct support person. To find out what they think about contacts with friends and family we read the files of 64 persons with PIMD. In the presentation we will tell more about the results and how they can be used to help people with PIMD to have better or more contacts with their friends and family.

## Children with profound intellectual and multiple disabilities in interaction with peers with PIMD and siblings

S. Nijs, B. Maes & C. Vlaskamp

It is important that children with complex support needs have the opportunities to interact with their peers and with their brother or sister. We wanted to know how these children interact with each other. We also wanted to know how the brother or sister tries to attract the attention of the child with complex support needs.

Therefore, we videotaped 14 children with complex support needs when they were together with another child with complex support needs. Afterwards we videorecorded the same 14 children when they were together with one of their brothers or sisters. We looked at these recordings and noted which behaviour is shown by the children with complex support needs and by the brothers and sisters.

The results will be presented during the congress. We think that children with complex support needs are more directed towards their brother or sister and that the brother or sister shows various behaviours to attract the attention of the child with complex support needs.

## Sympsoium 1.9. Engaging People with ID in Research

### People with intellectual disability (ID) and phenomenological research: a review of the literature

D. Corby, L. Taggart & W. Cousins

Aim: To look at some research that was done only with people with intellectual disability.

Method: This paper looks at nineteen pieces of research that involved asking people with ID about different experiences in their lives. This was done by firstly finding the studies and then going through them one by one to see how they were carried out and what types of things they looked at.

Results: Research involving asking people about their experiences is being done with people with ID. Those doing the research are influenced by different things such as particular ways of carrying out research. But things such as the country were the research happens can also be important. People who carry out research have to sure they are doing it in a way that is fair and can be a help to people with ID.

Conclusion: People with ID have and can be included in research that asks them about their experiences. The results can help those who work with people with ID to understand their needs and help improve services.

### How to meaningfully include children and young people with ID in research

K. Oulton, S. Kerry, L. May, D. Sell, C. DeSousa & F. Gibson

# Doing research together: a study about the views of people with intellectual disabilities and non-disabled researchers that collaborated in a research about transition to adult life.

C. Puyalto, M. Pallisera, J. Fullana & M. Vilà

This paper is about advisors with intellectual disability (ID) and researchers collaborating on a study about transition to adult life of young people with ID in Spain. We present the views of advisors and researchers on:

- What this experience represented for them,
- What they learned about doing research together.

The views of participants are obtained through questionnaires, group interviews and focal groups. Advisors valued this experience as an opportunity to learn, to freely express and to do something important. Researchers agree that this experience contributed to improve the quality of research. This research has allowed us:

- to learn more about inclusive research
- to improve future experiences.

# Symposium 2.1. Sexuality and People with iDD – 1

## People with intellectual disabilities talk about sexuality: important implications for the development of sex education

D. Schaafsma

## Sexuality and privacy among people with an intellectual disability: a qualitative study

J.M.T. Stoffelen, N. Hermans, D. Schaafsma, G.J. Kok & L.M.G. Curfs

## Using picture books to help people with intellectual disabilities learn and talk about sexuality

S. Hollins & I. Tuffrey-Wijne

## ‘Accidental counsellors’: transition staff supporting the sexuality of young adults with intellectual disabilities

N. J. Wilson & P. Frawley

## Sympsoium 2.2 Sexuality and People with IDD – 2

### Becoming the sexual person I want to be: an analysis of young adults' with intellectual disabilities' experiences, understanding and use of sexuality and relationship education and information

P. Frawley & N.J. Wilson

### Family caregivers' responses to sexuality and relationship support needs of young adults with intellectual disabilities

C.K. Kahonde & J. Mckenzie

### Identifying effective methods for teaching sex education to people with intellectual disabilities: a systematic review

D. Schaafsma

### Women who love: an explorative study on the lived experiences of lesbian and bisexual women with a mild intellectual disability in The Netherlands

J.M.T. Stoffelen

# Symposium 2.3 Siblings of People with IDD

## Exploring the differences in carer strain in sibling and parent carers of older people with an Intellectual Disability (ID) in Ireland

M. Griffith, P. McCallion, S. Doherty, E. Cleary & M. McCarron

The research was done in Ireland on family carers of older people with an intellectual disability. The researchers wanted to know if brother and sister carers found caring to be more difficult than parent carers did. The research showed; Most people who found caring to be difficult were brothers and sister carers. Parent carers seemed to find caring easier to do.

Carers who have their own health problems found caring to be more difficult. Having to do more things for the person with an intellectual disability made caring harder for carers. This research will be useful in helping sister and brother carers to continue providing care for people with an intellectual disability as they age.

## Self-reported behaviour problems and sibling relationship quality by siblings of children with autism spectrum disorder

R.P. Hastings & M.A. Petalas

## Adolescent siblings of children with intellectual and developmental disabilities in Norway: unique experiences and typical childhood

J. Tøssebro& P. Kermit

## Caring for an adult sibling with intellectual or developmental disabilities: factors affecting the decision to assume care

A. Zendell & P. McCallion

# Symosium 2.4. Communication and Language Issues for People with IDD

## Training parents to support the communication and participation of children with intellectual disability who use a speech-generating device (SGD)

K. Anderson, S. Balandin & R. Stancliffe

## Maintaining a Dyad between a Toddler with Communication Disorders and his Parent as a Primary Caregiver using Augmentative and Alternative Communication

A. Neeman & O. Hetzroni

We had two groups of families. In the first group, 21 families participated in the program and got many ideas for communicating with their children. We wanted to know the effects of the program, so we compared between them and another group of 19 families. This group learned how to do baby-massages to their children. We visited the families at their home and videotaped them in different activities to see what they were doing with their children.

We found out that our communication program helped all the parents and their children. Parents listened more to their children and learned to understand them better. And the children learned to answer and spoke more when their parents spoke to them. All the families enjoyed the programs and wanted to learn more about different ways to communicate with their children. We will explain how we gave ideas to the parents and how it helped them all communicate better.

## Systematic review of parent-implemented language interventions

D.te Kaat-van den Os, M. Jongmans, M. Volman & P. Lauteslager

## The role of Speech-Language Therapists in adults with Intellectual Disability.

C. Tod, J. Pahl & S.B. Karrim

Speech therapy or Speech Pathology is helpful for all people with Down syndrome. Many children with Down syndrome have Speech therapy but not when they are adults. This talk looks at how Speech therapy can help adults with Down syndrome. Five people with Down syndrome were asked about the problems they have with speaking. Children with Down syndrome have Speech therapy to help them speak clearly and learn new words. This is important so that they can go to school and learn new skills. Going to school can help them to get a job. Adults with Down syndrome can have Speech therapy to:

- learn about how to talk to other people at work,
- make their reading and writing skills better
- learn different ways of talking to other people.

Not everyone understands how Speech therapy can help. Speech therapy can help a person with Down syndrome no matter what age they are.

## Symposium 2.5 Positive Behaviour Support, Art and Sport

### Positive Stories: Implementing the Positive Behaviour Framework in Western Australia

M.G. Edwards, M. Cubbage, C. Soo, J. van den Akker, J. Hollick, C. McIver & F. Buchanan

Aims:
This paper is about a way of helping people with disabilities in Western Australia called the Positive Behaviour Framework (PBF). The paper shows how disability services are being changed because of the PBF. PBF is a government plan for improving helping disability services. People who face special problems need to have special help and the PBF helps services to give that help. We show how taking a positive approach to problems can be better than other ways.

Methods:
We describe the story of how PBF came to be and talk about the different ways it is used.

Results:
We tell some stories about how this approach can be used to help people in different situations.

Conclusions:
We hope this presentation inspires others to look at the PBF and see how they can use it to help people with disabilities.

## Stability of esthetic preference of landscape and portrait art images and photographs in people with intellectual disability

S. Stickel & G. Weber

People with ID are asked rarely about the beauty in paintings and photographs. We wanted to know how people with ID experience paintings of faces and landscapes.

Therefore we asked 20 people with ID and 20 people without ID to sort landscape paintings, portrait paintings, landscape photographs and portrait photographs, which paintings they like more and which they like less. We wanted to know if there are differences in this judgment between people with ID and without ID two weeks later.

So this procedure was repeated with an additional task at the beginning:
all participants were shown pictures they have already seen two weeks before and new pictures.
They were asked to decide which picture they have already seen.
After that they were asked to sort the pictures they had seen two weeks before one more time and tell us which they liked more and which they liked less.

We expect to find differences between people with ID and people without ID after two weeks as well as differences between the experience about the paintings and photographs.

This understanding can show the importance of cultural participation and inclusion for people with ID.

## Effects of inclusive sports in Austria

H.Tippl, M. Hirschberger, O. Leick & A. Weiss

We need to have information and good examples about the possibilities and opportunities of common sports activities from students with and without handicap in schools. We came up with a survey to find out which good examples of sports do we have in schools.

The method of the survey is called “action research". The survey is made up of three case studies about good examples of inclusive sports activities in different schools. The authors of these studies described the experiences with and the results of inclusive sports.

We found out that all involved people like teachers, parents, students with and without handicap very interested in taking part in inclusive sports events.
We also found out that you can do inclusive sport everywhere and with everybody. Inclusive sports is also good for the the climate in the classroom, for the development of self-esteem of all students.

Positive effects:
An inclusive PH teacher is eployed by the Styrian government and can help to do inclusive sports in Styrian schools More than 25 schools are taking part in inclusive sports events.

There are a lot of schools in Europe doing inclusive sports.

# Symposium 2.6. Families and Parenting

## Parenting in families of school-aged children with autism spectrum disorder: an observational study

H. Boonen, G. Lambrechts, J. Maljaars, I. Zink, K. Van Leeuwen & I. Noens

Raising a child with autism can be very challenging for parents. These parents often have to use different and more specific strategies than parents of children without autism. Some parents experience more stress, due to the difficulties they encounter when raising their child with autism. To date, we do not know much about observable parenting behavior in families of children with autism. For this reason, we are interested in two important questions:
Do parents of a child with autism use different strategies than parents of a child without autism when raising their child
Are these strategies influenced by certain characteristics of the child, for example behavior problems of the child?

We did observations to find out which strategies parents of children with autism use. We visited 30 families of a child with autism and 40 families of a child without autism at home. All children were between 7 and 11 years old. We asked the mother and their child to do three different tasks together. The tasks were videotaped. Afterwards, we evaluated which parenting strategies the parents used in these tasks.

We found that parents of a child with autism used different, but also similar parenting strategies compared to parents of a child without autism. For example, they used less expressions of warmth (for example giving a compliment) than parents of a child without autism. In the next step, we will find out if these parenting strategies are influenced by characteristics of the child.

## Exploring parenting behaviour in families of children and adolescents with autism spectrum disorder and/or intellectual disability

J. Maljaars, G. Lambrechts, H. Boonen, K. Van Leeuwen & I. Noens

Aims: Raising a child with autism or intellectual disability can be difficult. Especially because many of these children show behaviour problems. We studied how parents raise their children with a disability compared to parents of a child without a disability. We also examined how the child’s behaviour problems are related to the behaviour of their parents.

Method: For the research, more than 1000 mothers living in Belgium and the Netherlands answered our questionnaires. Their children were between 6 and 18 years old. About half of the children were diagnosed with autism or intellectual disability.

Results: We found that mothers of children with autism reported to raise their child differently in some aspects than parents of children without autism. For example, mothers of a child with autism were less likely to set rules or use discipline. They spent more time imposing so-called positive parenting (supporting your child, giving compliments and so on). A number of child and family factors were related to behaviour problems in children with autism. Younger children showed more behaviour problems, for example aggression. Behaviour problems were also linked to more harsh punishment and less discipline from the parents. The results on children with an intellectual disability will be available at the time of the conference.

Conclusions: Many mothers reported important strengths in adjusting their behaviour to the needs of their child with autism. Programs focusing on parenting skills may be helpful in reducing behaviour problems.

## What do families from ethnic minorities with children who have an intellectual disability need from local authorities: a report from Rotherham

A. McClimens, J. Brewster & R. Lewis

## The experience of motherhood by women with intellectual disabilities

A. Wołowicz - Ruszkowska

Method:
Conversations with 20 women with intellectual disabilities

Results:
This study shows how women with disabilities feel as mothers. This study is important because it reveals new problems in the topic of disability in Poland. There are three important themes in the conversations:

1. People do not like when disabled women want to have children. The women said that when a person is an adult they should make their own decision about their lives.
2. The women also said that people with disabilities have equal rights when it comes to deciding how many children they want and when they want them. Children should not be taken away from their parents only because their parents are disabled. It was clear that women feel discriminated. Discrimination means that people are treated worse because they have a specific feature, e.g. disabilities.
3. Other people should support disabled mothers and her children. The women do not feel supported, they feel that other people make decision for them.

Conclusion: This study proved that motherhood is a difficult experience for women with disabilities.

# Symposium 2.7. Communication & Story-Telling with People with PIMD

## Developing German Traditional Folk Stories into Multi-Sensory Experiences: Cross Cultural Exchanges and Shared Knowledge and Expertise

B. Fornefeld

The UN Convention on the Rights of People with Disabilities (CRPD) wants cultural and social participation for all people. This means people with disability are an important part of their community and culture. Severe cognitive and physical impairments prevent persons with PIMD from experiencing this participation. Stories appeal to all people, young and old, not disabled, or disabled.

We make traditional fairy-tales understandable for people with PMID. Language, props, music, and dramaturgy are changed. Now all persons are able to experience the story with their senses. This type of storytelling is called "mehr-Sinn® Geschichten". The German and Scottish stories are translated into the target languages. The narrators are trained to tell “mehr-Sinn® Geschichten". Then, the “mehr-Sinn® Geschichten“ are told to children, adolescents, and adults in the other country.

Video analyses prove that “mehr-Sinn® Geschichten“ can be transferred into other countries and can contribute to cultural and social participation.

# Communication breakdowns and repair strategies among children with severe intellectual & developmental disabilities

O. Hetzroni & M. Shalev

We wanted to check how children with severe intellectual and developmental disabilities (SIDD) communicate with their teachers and check if they understand their teachers, and if their teachers understand them. We also wanted to know if teachers that teach them every day will be able to understand them better than teachers that meet them only once a week.

We videotaped 12 children in school during class hours and looked at how they communicate with their teachers.

We found out that very often the teachers don't understand them and that they don't manage to explain themselves well to the teachers. The children answered more questions when the teachers asked them to but they did not ask the teachers many times. Teachers that see the children every day and teachers that meet with the children once a week were similar in their understanding of the children.

However, the teachers that met with the children every day asked them more questions when they did not understand them.

## Adapting traditional Scottish folktales in a multi-sensory way and using and evaluating them in schools and adult services for people with profound intellectual and multiple disabilities

M. Phillip

## The benefits of participating in exchanges between two organisations and universities: the outcomes for people with profound intellectual and multiple disabilities

H.Young, L. Lambe & M. Phillip

# Symposium 2.8. Accessible Communication and Information for People with IDD

## The Easy Read Project: an investigation into the accessibility value of health-based 'easy read' literature

S. Buell, K. Bunning, P.E. Langdon & G. Pounds

Aims:
We all need information to help us make decisions about our health. Sometimes this information is written down. 'Easy read’ information is made with language that people can understand. It usually has pictures. This study will show what makes 'easy read’ information easy to understand for people with learning disabilities.

Methods:
We looked at the 'easy read’ information made by the Department of Health in England. Then we looked closely at the language that was used in this 'easy read’ health information. We looked at the kinds of words and sentences that were used. We also looked at the kinds of words and sentences that were used in information that was not 'easy read’.

Results:
We found that 'easy read’ information uses more simple language than information that was not 'easy read’. We also found that sometimes the kind of language used in 'easy read’ information is less inclusive than information that was not easy read.

Conclusion:
We need to change how we make 'easy read’ information. In the next part of the study we will give some 'easy read’ information to people with learning disabilities to see if it is easy or difficult for them to understand.

# Television viewing habits and preferences of adults and young people with intellectual disability: a survey using a Talking Mats® - Questionnaire

K. Bunning, R. Davies, J. Greenwood, E. Sturman & C. Toner

What does watching television mean to people with intellectual disability?

We asked 28 adults and young people some questions:
- When do you like to watch television – morning, daytime or evening?
- Do you watch television in your front-room, bedroom or kitchen? With your family or friends, or on your own? Having a chat or being quiet? Having a drink or something to eat?
- What television programmes do like the best? Which ones are worst?

We used Talking Mats® to ask people our questions.People put pictures on a mat to tell us if they liked or didn’t like something. We filmed people doing this and checked what people said.

We found that everyone liked to watch television. The people who found speaking the hardest, watched the most television. Many people liked to chat when they watched television. Having something to eat and drink was also popular. Watching 'Soaps’, such as 'Eastenders’ and 'Coronation Street’, were the favourite types of programme. Most people did not like the 'News and Politics’.

Television means more than just watching a programme. It means chatting, eating, drinking and being with family and friends.

# Effectiveness of Computer-Based Simulations on Learning of Social and Communication Skills by Children with IDD and ASD

O. Hetzroni, T. Peleg & K. Shalahevich

In this study we wanted to learn how a computer program could help children with autism and developmental disabilities learn social and communication skills in their schools.

We created a program that could teach the children how to say hello when they meet someone in the school hall, how to answer a phone when someone calls, and how to play with a ball in the school yard.  We went to 6 schools and taught 85 children how to use the program. They could play with the computer program for 10 minutes every day and we checked to see if they learned to communicate and play better after learning with the program. We videotaped them in the yard, in the school hall and while answering the phone.

We found out that using the computer for teaching was very helpful and that all the children were able to learn to play better with the ball, they could say hello better in the school hall and some of them were better in answering the phone.

## Participation of individuals with ID in social media

C. N. Shpigelman & C. J. Gill

We want to learn how people with intellectual disability (ID) use Facebook:
What do they do on Facebook?
What are their difficulties on Facebook?
What do they need to make Facebook accessible?

We came up with an Internet survey to find out how people with ID use Facebook and how they feel when they use it. The speech will be about this survey. The survey was made up of 49 questions about Facebook. We asked any person with ID who uses Facebook to complete this survey on the Internet, and 58 people volunteered to complete the survey.

We found out that the people that completed our survey use Facebook: every weekwrite to friends and family members enjoy using it People with ID also said that reading in Facebook is difficult for them and they want Facebook to have easy words and more pictures.

## Symposium 3.1. Support Plans and Future Planning for People with IDD

### Future Planning for People with Intellectual Disabilities and their Ageing Family Carers in Switzerland

J. Adler & M. T. Wicki

Aim: Many people with intellectual disabilities live at home with their families. When their parents grow older, planning for the future is important. Because mothers and fathers are getting older and they are no longer able to support the person with disability. For these families it is difficult to make plans for the future. We translated a training programme to support the parents and their disabled sons or daughters in their future planning. We examined whether our training helps the parents and the person with ID to start with the planning for their future.

Method: At first the families get some information about important law and about money they can obtain. After that the training takes part in five afternoons. We asked all persons who took part about their planning. We asked them once before and once after the training. So we can see what the families can do with the help of the training. We compared these families with families who did not take part in the training.

Results: The families who took part in the training start the planning for the future by writing a letter of intent. And the parents discussed plans more often with their disabled relatives.

Conclusion: The training programme helps individuals with disability and their parents in planning for the future.

## Content analysis of individual support plans for people with intellectual disabilities

M. Herps, W.H.E. Buntinx & L.M.G. Curfs

## Life designing with intellectual disability: domain-specific goals and determinants in adolescents and young adults with intellectual disabilities

T.M. Sgaramella

## Future time perspective in parents of children and adults with intellectual disability: the role of future planning and quality of life dimensions

T.M. Sgaramella & L. Ferrari

# Symposium 3.2 Parenting and Families

## Parents with intellectual difficulties in Norway: an explorative study

B. Berg, V. Paulsen, T. Midjo & J. Tøssebro

## ‘You’ve seen us!’: Masculinities in the lives of boys with Intellectual Disability (ID)

D. Charnock & P. J. Standen

We need to have information about boys with intellectual disabilities and how they think about themselves. For example, we need information about:
What ideas boys with intellectual disabilities have about being boys?
How do they think about becoming a man?
We asked boys with intellectual disability to look at photographs of men doing lots of activities, including work and leisure activities, and asked them to talk about this in small groups.

Also, we asked the boys to draw pictures of what they thought their lives would be like as an adult and asked them to talk about this.

The speech will be about what happened.
This work was carried out with boys from a special school in the UK.

We talked to them in groups about the photographs and on their own about the picture they had drawn.

We found out that boys had ideas about being a boy, but this was sometimes difficult as they often didn’t have many chances to find out about new things. We also found out that the difficulties the boys had sometimes made them feel helpless.

We came up with some ideas that we think might help boys and men with intellectual disabilities have more hopeful futures.

## A qualitative analysis of the experiences and needs of parents supporting young adolescents with intellectual disability through puberty and emerging sexuality

J. O'Neill, F. Newall, S. Lima & K. Thomson

This project was about how parents of teenagers with intellectual disability feel about their child growing up and what support would help. Six mothers of teenagers with intellectual disability were spoken to.
The things mothers talked about were:
-how hard it is for a teenager to understand what is happening with their body
-being worried about their child's safety, and
- how hard it was to think about the future for their child.

We have learnt that parents feel more comfortable with body changes than behaviour changes in their child. Parents would like more help as their child gets older.

We will use this information to change the way we support parents and teenagers with intellectual disability.

## Symposium 3.3. Subjective Well-Being and Quality of Life

### Subjective well being and its correlates among adults diagnosed with comorbid ID and ADHD

T. Araten-Bergman

We wanted to understand what helps people with borderline ID and Attention Deficit Disorder (ADHD) feel good about themselves and what is important to them in their life.

We used the theory of Subjective Well-being Homeostasis and asked 246 man and women to tell us how happy they are with different things in their life (like friends, money, health, work, etc) and how happy they are in their life as a whole.

We found that:
Man and women with ID and ADHD are just as happy as people without disability.
Man and women say they are happy with their life as a whole.
Different things are important for men and women:
- men felt happier when they had more money
- women felt better when they had more friends

Our findings help us to understand what makes people happy and may help us to assist people to achieve things that are important for them and makes them happier in their life.

## Bio-psychological, Family and school factors in childhood as predictors of adult success and quality of life of persons with borderline IQ

A. Firkowska-Mankiewicz & G. Szumski

## Youth and adults with intellectual and developmental disabilities: their own perceptions about their quality of life

V. Vega, J. Benavente, J. Lopez & M. Flores

## Empowerment of self-determination

A. Wiese

## Symposium3.4. Self-determination, social planning, mutual caring and volunteering

### An exploration of mutual caring relationships involving an individual with Intellectual Disabilities (ID)

A. Parr

We need more information about carers with intellectual disabilities (ID). More people with ID are becoming carers for people who might need help, like older parents or other people in the family.

This is because more people with ID are living longer and are living with older family members. It can sometimes be difficult for carers with ID. Some carers can often feel lonely and feel that people like social workers do not understand that they are a carer.

I have talked to people who work with carers and people with ID. I have also talked to carers with ID and the person they care for. I think it is important to find out what it feels like to be a carer with an ID and what support is around. This will help us understand more about carers with ID. Not many carers with ID have been spoken to about their feelings and experiences.

This research aims to make things better for carers with ID. I will do this by looking at the support and services available to carers with ID and by trying to get more people to understand that people with ID can be carers too.

## Considering weak interests - participative practice in social planning strategies with persons with ID

M. Katzer, S. Schäper & S. Frewer-Graumann

Aim: Planning of social services often is not considering the interests of persons with disabilities themselves. Especially the influence of persons with profound and multiple disabilities is limited. The research project “SoPHiA" tries to focus so-called “weak interests" of elderly persons with disabilities.

Methods: The project tries to realize different methods of participation like interviews, group discussions, workshops, open space discussions in the community. Weak interests should be considered in social planning.

Results: Persons with “weak interests" can be enabled to participate and to tell their vision of living in the community. They know their own needs for social services, daycare and leisure activities and social relationships very well.

Conclusion: The participation of all service users is necessary for planning adequate and inclusive service arrangements for elderly persons with and without ID.

## Self-determination: conceptions of youth and adults with intellectual or developmental disabilities

V. Vega & J. Benavente

## Supporting Volunteering Activities by Swiss Adults with ID

M. T. Wicki & S. Meier

Aim: The study explores challenges, opportunities and support needs of volunteers with ID.

Method: An online survey was send to placement offices and service organisations for people with ID in Switzerland.

Results: Only few people with ID are engaged as volunteers. People with ID need appropriate support to be able to volunteer.

Conclusions: Services need ideas and support to develop tailored activities. Services need information on how to offer specific forms of recognition.

# Symposium 3.6. Growing Older and People with IDD – 1

## End of life care for people with intellectual disability

R. Hussain, S. Wark & T. Parmenter

## A GIS-based planning tool for the socio-spatial analysis of the elderly population with and without disabilities and their support

B. Rodekohr & F. Dieckmann

We want to know how elderly people live in the community. We need to have information about the number of elderly people with or without disabilities. We also need information about support services, for example: assisted living services and locationsnursing homesgroup homesleisure facilitiescounseling servicesvolunteer agencies.

We collected data from disability services and the elderly care system.  We also used demographic information. This information was collected  in a Geographic Information System (GIS). The GIS system can picture the data on a map.  GIS helps planning bodies to get an overview of structures within the community. It shows which services are missing. GIS helps to find out which services can be combined. So services can be used by all elderly persons with and without disability. This overview helps planning bodies to think and plan in an inclusive way. They can see the needs of all elderly people. The overview shows what elderly people need to live,to age and to die  in their familiar surroundings.

## Inclusive social planning for elderly persons with lifelong disabilities in the community

S. Schäper, C. Rohleder & F. Dieckmann

Aim: Persons with and without disabilities need support to live in the community when growing older. Planning the best arrangement of support has to be an inclusive process. Everyone should participate in planning conferences.

Methods: Interested citizens and stakeholders in two communities came together. They talked about the needs of elderly persons. They will try to find solutions for problems, so that everyone has the chance to age in place.

Results: If everyone has the possibility participate in planning, support services will meet the needs of elderly persons.

Conclusion: All stakeholders have to work together to guarantee quality of life for a growing number of elderly persons with and without lifelong disabilities in the community.

## Written Policies on End-of-life Care in Residential Homes for Adults with ID

M.T. Wicki, S. Meier & J. Adler

Aim: Residents in residential homes for people with ID are getting older. Our interest was in finding out if the residential homes are prepared.

Method: A survey was conducted.

Results: Written policies on end-of-live care are available in only a fourth of the residential homes. Little training on end-of-life care has been conducted.

Conclusion: It is important to develop written policies. It is also essential to provide more staff training on end-of-life care.

# Symposium 3.7. Growing Older and People with IDD – 2

## Ageing-in-a-chosen-place: commonalities and dissonance in life choice-making in elders with and without intellectual disability

R. Hussain, T. Parmenter, M. Knox, M. Janicki, C. Leggatt-Cook, S.Wark, M. Cannon, M. Edwards & M.Parmenter

## The Relationship of Person-Environment Fit to Older Adults' Perceptions of Autonomy, Competency and Satisfaction

B.L. Hutchings

Aims: When people with lifelong disabilities get older, they face the challenges of aging at the same time that face the challenges of having a disability. This study explored the experience of aging with a lifelong disability.

Methods: We asked people who were aging with lifelong disabilities to talk with us about their experience. All the people we talked with were living in houses and apartments in the community. We asked each person to share their feeling about their homes. We wanted to find out what was working well for people and what things could be better.

Results: We found that it was important to people to be as independent as possible and to be able to do things on their own. Some people told us about ways they were able to be dependent. Some also talked about things that made independence hard for them. People told us it was important for them to feel that they belonged and to have their own things. People liked staying in one place instead of moving around a lot.

Conclusions: People need houses and apartments that help them to do everyday tasks as independently and safely as possible. When the home is planned to meet the needs of the people who live there, people are able to do more for themselves and feel better about their abilities.

## Exploring carers' experience of end of life for people with ID as they age

J. O' Farrell

Aim: To explore carers’ experience of death of adults older than 40 with ID in Ireland.

Methodology and results: 40 people have died since the first part of the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing. Carers of people who died were interviewed about the end of their lives. 17 women and 23 men have died and their average age was 61.8 years. Most people who died had a moderate (50%) or severe or profound (42.5%) ID. Carers provided information on the care that people received and this will be described.

Conclusions: Results will help to change how people with ID are cared for at the end of their lives.

## When aging in place is no longer viable: transitions to a higher support home for persons with an intellectual disability and dementia

P. Dunne, E. Reilly & M. McCarron

# Symposium 3.8. Ageing, Retirement and Longevity in People with IDD

## Retirement from Mainstream Employment: Older workers with ID and their plans for life after work

M.Brotherton, R.J. Stancliffe & N.J. Wilson

In Australia, Disability Employment Services support people with intellectual disability to work in mainstream jobs. Many workers supported by these services are now getting older. We wanted to find out what plans they had for retirement.

We interviewed 14 people over 40 years old with intellectual disability. We asked them what they think about retirement. We asked what they would like to do when they have retired from work. We also asked them about the family, friends and other people that support them.

Some things we found were: People wanted more information about the activities in their community they could choose from;
Getting transport to community activities was a problem for many people;
Some people we interviewed already had clear ideas about community activities they would like to do.
For some activities like being a volunteer, they would need support. We weren't sure about who would be able to give them the support they would need.

We will use the information from the interview to develop a program for older workers with intellectual disability. The program will support them with planning to move from paid work into retirement.

## Life expectancy of persons with intellectual disabilities (ID) in Germany estimated by exponential regression

F. Dieckmann, C. Giovis & I. Westermann

The number of elderly persons with intellectual disability is growing. To be able to support them, service providers need to know how many elderly persons with intellectual disability will live in Germany in the future.  For a good estimation, the researchers looked at how old persons with intellectual disability were when they died. The average life expectancy tells us how long most persons with an intellectual disability usually live.

In the group of persons from Westphalia-Lippe, the average life expectancy for men was 71 years. The average life expectancy for women was 73 years. In Baden-Württemberg the average life expectancy for men was 65 years. The average life expectancy for women was 70 years. Most persons with intellectual disability are getting older today than they used to in the past.

Similar research projects have come to the same findings. Still, most of them die younger than persons with no intellectual disability. Most women with intellectual disability are getting older than most men with intellectual disability. But the difference is not as big as it is when men and women without intellectual disability are compared.

## Looking at ageing and retirement options for adults with intellectual disabilities

L. Hanna-Trainor & L. Taggart

## Development of a support program for relatives of seniors with intellectual disabilities in Norway

F.K. Larsen & K. Hotvedt

## Symposium 3.9. Movement, participation and QOL for People with PIMD

### Profound intellectual and multiple disabilities

T. Boren, A.K. Axelsson & M. Granlund

### Motor Activation and the Role of Theory in People with Severe or Profound Intellectual Disabilities

S. Houwen, A. van der Putten & C. Vlaskamp

Physical therapists can help people with severe or profound intellectual disabilities to learn how to use parts of their body and to move better. Physical therapists all use their own techniques in helping persons  with severe or profound intellectual disabilities to move better. We want to know on which ideas physical therapists base their treatment for people with severe or profound intellectual disabilities.

We searched in books and journals to get information about the ideas that physical therapists use to base their treatment on. We also talked to many physical therapists. The speech will be about the information we found.

We found out that little information was present in books and journals. The physical therapists told us that they find it important to look in books and journals for ideas for treatment, but many of them do not really do this.

## Evaluating quality of life of children with multiple disabilities: issues and methodological questions

R. Scelles, C. Dayan, C. Arnaud, A.M. Boutin, M. Storme & G. Ponsot

## Practice-based movement-oriented interventions in people with profound intellectual and multiple disabilities: lessons to learn

A. van der Putten

## Symposium 1.1: Supported Employment

### Supported work experience and its impact on young people with intellectual disabilities and their families

S. Beyer, A. Meek & A. Davies

## Age peer supported work experience and apprenticeship and their impact on young people with intellectual disabilities, peers and employers.

A. Davies, S. Beyer & A. Meek

We looked at two studies. First we looked at age peers supporting 45 young people with intellectual disabilities in work experience placements. We asked where the placement was, what the employer thought about it and how well it worked. Secondly we looked at 4 young people doing an apprenticeship in a hospital. We asked the managers, young people and their families what they thought about it. We also asked about how well they did, how they got on with other staff and if they got paid jobs at the end. We collected information from the Real Opportunities Project, which works with young people aged 14-19 years old who have an intellectual disability or an Autistic Spectrum Disorder. The project helps young people in preparing to leave school and finding employment. We found that having a peer supporting them was a positive thing for the young person, peer and employer. Peers learned more about people with intellectual disabilities and learned new skills that would help them get jobs. Employers were very pleased with the performance of young people and peers. Three of the four apprentices got paid jobs at the end.

## Personalised employment support for people with intellectual disabilities

M. Stevens & J. Harris

## Approach to cost-benefit analysis between supported employment and special employment centers through comparative simulation with 24 workers

F.B. Jordán de Urríes, D.de León, F. Hidalgo, S. Martínez & M. Santamaría

## Symposium 1.2: Transitions into Employment

### Experiences of participation of young people with intellectual disabilities in the transition process from school to working life

H. Fasching

Aims: There is little information about the biographies of people with intellectual disabilities. We wanted to know to what extent young people with intellectual disabilities can participate in the transition process from school to employment.

Methods: The experiences of school leavers from special schools and from inclusive schools were compared. We asked eight persons with intellectual disabilities about their experiences of participation in their transition from school to working life.

Results: Support from family and friends is very important in the transition from school to working life. The social background of young people with intellectual disabilities is also very important. It is often a disadvantage in the transition from school to working life.

Conclusion: We must pay more attention to the aspect of social discrimination of people with intellectual disabilities.

## Workshop/course for people with learning disabilities

A. Abdullahi & C. Norllin

People with intellectual disabilities are often excluded from the jobmarket. In Sweden, the unemployment rate stands at 80% among students who have finished special school. In this field study, we created a series of varying workshops for six participants with intellectual disabilities focusing, on understanding and learning the fundemental basics of how to get, and keep a job. The workshop-series had three objectives: Improve and enhance the participants' confidence before meeting an employer; improve the participants' knowledge about work; and in the end, to increase the labor market participation among the students.

Method: We developed a questionnaire that would measure the participants' experience and attitudes towards the labor market. The questionnaire consisted of eight different areas. Participants answered the questionnaire before and after the course. We compared their experience and employment status with a control group consisting of six other randomly selected individuals with intellectual disabilities that did not participate in the course. Both of these groups received regular supported employment support.

Result: The participants' readiness to enter the labor market had become more positive. The participants' employment rate also increased compared to pre-test levels and the control group.

Conclusion: This study demonstrated that we can increase labor market participation among persons with intellectual disabillities with work related workshops.

## Transition to employment by young people with development al disability: Family hopes and expectations in rural communities

K. A. Willsher

Research often shows that unemployment is high among young people with intellectual disability. The move from school to a secure job is often hard because of prejudice and problems with community services especially in rural areas. We need a better understanding of the difficulties young people intellectual disability face in rural areas of Australia.

Parents and families of young people that had disability were interviewed to find out about the difficulties young people with disability have in getting a job. The speech will be about these interviews. The interviews showed that the move to employment by young people with disability was difficult because of prejudice and families, services providers and employers not talking very much to one another. Families were worried about their son or daughter’s future wellbeing. There were also concerns that employment in sheltered workshops was poorly paid and repetitive. However, the people that were interviewed felt that both young people with disability and employers need to have realistic expectations and to be well prepared. Good communication between the young person with disability, the family, service providers and employers is important to help achieve meaningful employment.

# New labour market - old gender roles. Working life after school for young adults with intellectual disability in Sweden.

J. Arvidsson, S. Widén & M. Tideman

We need to know more about the post school labour market situation for young Swedish men and women with intellectual disability. For example, we need to know: Which men and women are in gainful employment? In what occupations do they work? How much do they work? Do their salaries differ? This study is based on information from three different registers, one newly created and two Swedish national registers. The registers contains a lot of information about many people.The speech will be about 2,745 men and women with intellectual disability who all have a job. The results from the study show that both the road to work and the situation at work differs between the men and the women. Small private companies are the main employers. Among the women, the public sector is also an important employer. Men and women are mainly employed in traditionally “male" and “female” professions. Also, salary levels and additional support from the state differ between the sexes. These results are important because Sweden is seen as one of the most equal countries in the world. But there is still an un-equal situation among men and women on the labour market. This is a fact for women and men in general, and this study shows that it is also a fact for the women and men who have an intellectual disability.

## Symposium 1.3: Getting into Employment for People with IDD

### Intellectual disability and gender in the transition from school to vocational training and employment

H. Fasching

Aims: In Austria there is not enough information about the transition from school to employment. As a result, men and women with learning difficulties are often invisible.

Methods: We collected information about the transition from school to employment in Austria. This should show how the transition from school to employment works for men and women with learning difficulties.

Results: The transition is influenced by the kind of school which a person attends and if the person is a man or a woman. The transition is more difficult for pupils from special schools. The transition is easier for pupils from inclusive schools. The transition from school to employment is even more difficult for women from special schools. The transition is easier for men from special schools.

Conclusion: Inclusion in school makes the transition from school to employment easier. Support in the transition from school to employment is very important for men and for women. This helps the pupils to decide where they would like to work.

## Employing people with intellectual disabilities in the public health workforce

L. Russ

## Project search UK – does it deliver employment for young people with ID?

A. Kaehne

## Barriers which inhibit transition from school to employment

F. L. Fea

Transition from school to work opportunities is not easy for persons with disabilities. There are many barriers to do so. A European project on this topic has been carried out by 14 organizations from 10 countries. The research identified a long list of barriers which are common in those countries.Main barriers are about teachers not always well trained, few opportunities to be employed in the open labour market, companies do not want to employ persons with disabilities. Discrimination is the main cross-cutting barrier.A toolkit and recommendations list will be presented as a strong proposition to decrease and remove those barriers.

## Symposium 1.4: Effects of Being in Employment for People with IDD

### Improvements in acute hospital care through employing people with intellectual disabilities

D. Marsden

### An exploratory study of the factors affecting integration and retention of persons with intellectual disabilities in open employment

A. Deshpande & A. Khare

## Employment, social capital and community participation among Israelis with disabilities

T. Araten-Bergman

We know that work and having people you love and trust is very important for living a good life. But we need to know more about how these things help us to feel better and to do more things in the community.

In this speech I will present what I found when I compared working people with disabilities to people with disabilities that are not working.

1. People who work say that they have more friends and family members that they love and trust than people that are not working.
2. People who work do more things in their community.
3. People who work say that they are happier.
4. People who say they know, love and trust more people are happier and do more things in their communities. These findings help us to understand how work, family, friends and the things we do for fun help us to feel happier.This can help us to find ways to assist people to learn how to meet more people, stay in work and to be more active in their environment, so they would feel better and happier.

## Employment in Down syndrome: The experiences of individuals with Down syndrome, their employers and families in South Africa.

C. Tod, J. Pahl & S.B. Karrim

There are not enough jobs for people with Down syndrome. This talk looks at how having a job helped five people with Down syndrome. Their bosses and family members were also asked about what working does for a person with Down syndrome. All the people with Down syndrome were happy that they had a job and were getting money. They said that their jobs help them to learn new things and to meet new people. The people with Down syndrome liked to use mobile phones, iPads and computers to talk to others. Some people with Down syndrome find it difficult to talk or to say what they think. Other people with Down syndrome cannot read and write and if they could they did not often read or write at work. This makes it hard for them to get a job but the law still says they can have a job if they want one. Some things that can help a person with Down syndrome improve the way they talk and learn are Speech-Language Therapy and going to school. Choosing the right type of job and having people to help is very important.

## Demonstrations About Services: Education

### Enhancing the transition from secondary school to postsecondary education for students with autism spectrum disorder

V. Van Hees, T. Moyson & H. Roeyers

### Intellectual Disability in Namibia

N. Niyazi & G. Weber

The speech will explain what is going on at the moment with regards to people with intellectual disability (ID) in Namibia. It will also tell us what the chances are of a good life for people with ID. People with ID in Namibia face similar challenges like others around the world do, like prejudice and not including them in important matters. However, poverty and HIV/AIDS make it much worse for people with ID in Namibia.The Namibian laws and the constitution are very friendly towards people with ID and the government wants to protect their rights, but what is going on in real life is not as good as it is in the law. For example, according to the law, children with ID must go to a normal school with other children, but they continue going to special schools. Due to the fact that there are very few special schools, many children with ID do not go to school at all. Abuse and neglect occur a lot too. Even though there are challenges, there are people in the community who are doing a lot and these projects show great promise. The speech will end with the need for information so that we can make good decisions that help people with ID.

# Learning opportunities throughout the lifespan: presentation of initial research findings

A. Veyre, G. Petitpierre, G. Germain & I. Bruni

# Health: General Health and Specific Health Issues

## Findings of an inquiry into deaths of people with ID: academics and people with ID working together to disseminate findings through film

A. Marriott & The Misfits Theatre Company, P. Heslop, M. Hoghton, P. Fleming,

P. Blair & L. Russ

In England, a study looked at whether some people with ID are dying too soon. The study found that poor quality care made some people with ID die sooner than they should. The people who carried out the study (the researchers) worked with the Misfits theatre group of people with ID to make a film about the findings of the study. The DVD tells the stories of John, Bill, Karen and Emily and what could have been done to help them live longer lives. In this session we will show the film, and the researchers and actors will talk about how we made the film together.

## Health competence training for people with intellectual disabilities

B. Brehmer-Rinderer & G. Weber

## Improving health care through twitterchats

D. Marsden, S. Abdulla, S. Wilson & M. Parker

## Practical understanding: an approach to making ideas accessible

N. Grove

Taking part in meetings and community activities can be difficult when people use complicated language. Symbols, pictures and easy read materials can help us to understand information. But sometimes they can be confusing too. In this presentation we will talk about language, understanding and communication. We will look at how understanding works for all of us. We can all get somewhere along the way to grasping ideas, even in a small way. We will explore a method for working with ideas that are important in social action. This approach was developed to help people enjoy literature and poetry. It involves drama, art and discussion.

## ‘Stop Motion' video: Mapping the stories of people with intellectual disabilities moving into community living

N. Salmon, E. Burns, C. Callaghan, J. Deegan, C. Keaver & S. Lee

Aim:

This video tells the stories of people with intellectual disabilities moving into homes they chose.

Why?

There are many ways to tell life stories. Researchers often use writing, but many people do not read. Using video instead of writing is a new and exciting way to share research stories.

How?

First, 27 stories from self-advocates in Ireland and Nova Scotia were heard.
Second, a team of self-advocates and supporters worked together to see links across these stories.
Third, we used a tablet and an app for ’stop-motion’ to make the stories come to life.

What We Learned:

Using tools like 'Stop motion’ help us tell the stories of people with intellectual disabilities without using words.

## Understanding the Support Needs and Priorities of People with Intellectual Disabilities from Minority Ethnic Groups: Topics of Concern, and Resources for Services

G. Unwin, J. Rose, B. Stenfert Kroese & M. Larkin

People with intellectual disabilities from minority ethnic communities are less satisfied with support services in the United Kingdom.
We wanted to look at ways we could help improve support. We asked 32 people with intellectual disabilities from minority ethnic communities about:

Their culture
Their support, for example, the things they get help with, who helps them, and services who give support
How they feel about their support
How services could improve.

The people we spoke to told us about things that were important to them. These things were grouped into 5 topics:

My culture
Good support
Independence
Important people and relationships
Activities and things I do

We made five videos about each of these topics to explain what the 32 people told us. We also made a set of 'tools for talking’ for people with intellectual disabilities to use with support workers. We hope the videos and tools for talking will help people think and talk about the things that are important to them. We hope this will help services plan their support.

In our session, we will show the videos and tell people about the activities.

## Using video-recording for research training: The experience of the Inclusive Research Network

C. Burke, B. Donohoe, M. Dooher, C. Gannon, E. García Iriarte, L. Phelan, R. Hopkins, M. McManus, G. Minogue, N. Salmon, P. Santry, A. Sexton, M. Walls & M. Wolfe

This session will show people the videos we used to train co-researchers with intellectual disabilities to do the Home and Independence study. The IRN conducted the study. It is important to include people with intellectual disabilities in research because:

What people know matters
The research has a stronger design
People have the right to be key players in decisions that shape their lives.
There is not a lot of information on the support people with intellectual disabilities use to take part in research teams
Most of the information is about using easy-to-read text and pictures
We do not know enough about other supports like role-plays and video.

This is a 10 minute session where we:
Show videos we used for training
Talk about what was it like for co-researchers and supporters
Give recommendations.

## Meaningful participation and inclusion of adults with profound intellectual and multiple disabilities in music therapy

J. Lee

In music therapy, people who have profound disabilities participate in a variety of musical activities.
They can listen to their favourite songs, play some musical instruments, and vocalise with a music therapist.
Using people's favourite music, music therapists meaningfully interact and build relationships with them.
In this presentation, I will show video footage of music therapy sessions conducted between five music therapists and their clients.
You will see how people with profound disabilities meaningfully interact with their music therapists.
I will also talk about common characteristics and benefits of these meaningful moments.
I hope my speech promotes more music therapy for people with profound disabilities in the future.

# Art for All...Free Art...Not Art Brut Only!

F.L. Fea

The purpose of the project is to enable equal access to art education for persons with disabilities.
Adults with intellectual or mental disabilities have many difficulties in being acceppted in the art world, even if well recognized experts.

This European project has been carried out by interviewing art facilitators, teachers, art critics and users from each partner's country. National seminars and itineratnt exhibitions were also organized.
A toolbox composed of a guide of good practices was created to facilitate communication between art facilitators and persons with disabilities.

This session will show how art schools can and should be open to persons with disabilities to enable them to be part of the world of art and also to give them the opportunity to express their creative spirit.

## Preconditions and Challenges for Participation of People with ID in Physical Activity, Dance, and Sport

M. Dinold

People with intellectual disabilities deserve equal rights as all other individuals. The UN Convention on the Rights for People with Disabilities (CRPWD) is promoting the dignity of all human rights and fundamental freedom for all persons with disabilities. This includes those with intellectual or learning difficulties. We want to arrange their life as good and pleasant as possible. Physical activity, dance and sport are very appropriate to do this. In this presentation some conditions are discussed which have to be considered when offering physical activity, sport or dance in specific. There are good experiences that Physical activity and dance can enhance well-being. Various levels of performance are possible and shall be demonstrated.

## Clearing plus support for self-determination

F. Tuppa

## ‘Bewohnervertretung’: resident representation for people with intellectual disabilities whose right to personal freedom is restricted

S. Jaquemar

## Theme: Health: General Health & Specific Health Issues

### Challenges in Health Surveillance

E. Emerson, H. Ouellette-Kuntz, C. Hatton & G. Glover

We need to know whether people with intellectual disabilities are healthy or not. In this session people from the UK and Canada will talk about what they have been doing to check on the health of people with intellectual disabilities in their countries.

## The development of European norms for palliative care of people with intellectual disabilities

I. Tuffrey-Wijne, L. Curfs, A. Dusart, C. Hoenger, L. McEnhill, D. McLaughlin, D. Oliver, S. Read, K. Ryan, D. Satgé, B. Straßer & B. Westergaard

## Primary health care and community based living

H.V. Schrojenstein Lantman-de Valk, A. Coppus, M. Mastebroek, E. Bakker-van Gijssel & M. Heutmekers

## Palliative Care for Adults with ID in Europe

M.T. Wicki, S. Meier, J. Adler, I. Tuffrey Wijne, M. McCarron & L. Probs

Palliative care is the important end-of-life care. People with ID face several barriers and disparities to palliative care.

At this roundtable five projects on palliative care for people with ID will be presented. Irene Tuffrey-Wijne, Mary McCarron, Laetitia Probst and Monika T. Wicki will present their projects. The projects will be discussed.

We will try to develop a European research project on palliative care for people with ID.

# Theme: Law and Liberty of the Person

## Access to specialised victim support services for women with disabilities who have experienced violence

S Mandl, C. Sprenger, A. Schachner, R. Traustadottir, S. Woodin, S. Sha & M. SchrÖttle

## Equal recognition before the law: reflections on the significance of Article 12 of the Convention on the Rights of Persons with Disabilities

M. Redley, I.C.H. Clare & A.J. Holland

## End-of-life issues and euthanasia and persons with PIMD

C. Vlaskamp& P. Rijkhoek

## Theme: Living in the Community

### The role of ideology in service development and design

J.D. Beadle-Brown & C. Hatton

In this session we will discuss the beliefs about how people with disabilities should be helped and about their rights in different countries.

We will talk about how these beliefs can help us understand the type of services available to people with disabilities in different countries.

We will also talk about how we can strengthen the belief that people with disabilities have equal rights to a life in the community.

We will also talk about whether reducing costs is important in different countries.

There will be four short presentations to help us thing about different ways of thinking about people with disabilities and their support.

# Social inclusion in the neighbourhood: bonding and bridging multiple perspectives

T. Overmars-Marx , A. Brummel, F. Bredewold, R. Taha Mcheimech & V. Cobigo

## Reducing the use of restraint and restrictive approaches to support ordinary community living

R. Deveau, A. McDonnell, P. McGill, K. Poon & L. Webber

Purpose: People with intellectual disabilities who show behaviour that staff find difficult to manage often live in institutions away from ordinary communities and are often restrained or locked in. We will discuss how research and how the law and government policies can help reduce restraint and other restrictions to help people live in ordinary communities.

Rationale: Many countries have government policies that say all people with intellectual disabilities should have the right help to be able to live in ordinary homes and communities. But we know from research that many people still live in institutions and are restrained or locked in and given drugs to sedate them, especially those people who show behaviour staff find difficult to manage. We will discuss whether government policies or changing the law can change people's lives and lead to less restraint.

Summary: We would like to help different countries learn from each other, to find the best ways to help people with intellectual disabilities and show behaviour that staff find difficult to manage, live lives with less restraint and restrictions. With the right kind of help we think all people can live as citizens in ordinary communities.

## Close collaborations with and within practice

P. Embregts & W. van Oorsouw

## Pushing the frontiers of knowledge in the field of parents and parenting with intellectual disability [1]: ‘there is nothing so practical as a good theory’

D. McConnell, M. Feldman, P. Granqvist, H. Sigurjonsdottir, L. Pacheco, G. Llewellyn & R. Mildon

## Pushing the frontiers of knowledge in the field of parents and parenting with intellectual disability [2]: utilising population-based and administrative data to push the frontiers of knowledge

D. McConnell, E. Emerson, G. Llewellyn, B. Horglund, T. Laliberte, G. Hindmarsh,

L. Hahn, M. Aunos & N. Wing Man

## A framework for an integrated process for improving quality of life

A. Schippers, I. Brown, M.A. Verdugo, D. Roth & L. Croce

## Theme: Participation Over the Lifespan

# Grounding people in their own reality

J. Clapton, M. Redley, K. Scior, D. Charnock & J. Clegg

## Education

### Areas of competence of future teachers developed within teacher education programmes towards inclusive education in Poland

M. Bielawska

### How does using mainstream technology impact the learning of practical academic skills in adults with intellectual and developmental disabilities?

C. Cederlof

# What Kind of Teacher for What Kind of School? "Special" Teachers and the Pathways to Inclusion in Italy during the 20th Century

A. Debè

In Italy, educational initiatives for persons with disability were developed at the beginning of 20th century.

In this period there was: the establishment of special schools for intellectually impaired; the investment on training for “special" teachers. The research analysed the “School for the special aids and assistants for disabled children", opened in 1926 at the Catholic University of Milan by father Agostino Gemelli. The methods used are archival researches. There were analysed: 5 archives; 350 letters; 300,000 data. The aim was studying teachers, users, materials of the School, since 1926 until the Seventies. The research found that: at the beginning of 20th Century there was a specific training for future special education teachers; in the Seventies this training has changed and mainstream schools’ teachers were not prepared anymore to educate disabled pupils in inclusive classrooms.

## Identifying the expressions of ecological self-awareness in children with profound intellectual and multiple disability: development of a setting of experimental and natural situations

J. Dind

## Determinant factors of quality of life of students with special educational needs – the role of resilience

B. Ruiz, M. Gómez-Vela, R. Fern_andez-Pulido & M. Badia

## The role of educational context on self-determination of students with intellectual disability

M. Gómez-Vela, C. Vega, R. Fernández-Pulido & M. Badia

## The influence of participation on quality of life of students with special educational needs

M. Gómez-Vela, B. Ruiz, M. Badia & R. Fernández-Pulido

# A Cross-cultural Comparison of Inclusive Education in Japan and Italy

S. Hashimoto, A.R. Takeshita & H. Goma

The aim of this study was to compare teachers' views on inclusive education in Japan and Italy. We handed out questionnaires about opinion on inclusive education to 52 Japanese teachers and 52 Italian teachers who work at public schools in Japan and Italy.

"What do you think about inclusive education in your own country?"
In both countries, 100.0% of teachers agreed with own inclusive education. Japanese teachers noted: "It is necessary to create suitable studying environment for each student's stage of development." Italian teachers noted: "The existence of students with disabilities in classrooms could be resource for students without disability to learn difference, acceptance, and respect."

"What do you think about Italian/Japanese inclusive education?"
25.0% of Japanese teachers agreed with Italian inclusive education and 3.8% of Italian teachers agreed with Japanese inclusive education. We found out that there is a difference in value of inclusive education between Japan and Italy, this difference probably shows the cultural, historical, and religious background of both countries. We also found out that more Japanese teachers seek another type of inclusive education than Italian teachers.

### The experience and meaning of special education teachers who teach in integrated stronghold vocational schools

S.A. Yoo, Y.O. Kim, D.H. Heo & K.W. Lim

### The use of Colourful Semantics to enhance narrative skills in children with intellectual impairment

S. Hettiarachchi, M. Ranaweera & L. Dissanayake

### The next logical step or still a revolution? Educating adults with ID to become ‘Social Care Helpers’ in the disability field

S. Gstettner, G. Hofer & M. Steixner

### Trend of video modeling studies for children with developmental disabilities

L. Jisun, B. Jeon & Y. Jo

## Evaluating the User Experience of Learning Tools with a Focus on the Pupils with Profound Intellectual and Multiple Disabilities

J. Kadastik

The learning tools do not take into consideration the needs of the children with profound intellectual and multiple disabilities. The creation of suitable learning tools must be based on user experience. In this study we need information about:
May the evaluating the user experience based on the taxonomy of behavioral categories?

During the study we videotaped pupils' activities in different situations.

We came up a questionnaire for parents and support workers. This questionnaire based on the taxonomy of behavioral categories. Were created individual profile of each child.

We found out that the taxonomy of behavioral categories will be possible to use.
It may be used as part of evaluating the user experience of learning tools. A further studies should look at ways to evaluate the user experience in a combined way. For example we will use the taxonomy of behavioral categories and a psychophysiological measurement.

## Examining executive function in children with autism with comorbid ADHD using the Wisconsin card sorting test

Y. Kado, S. Sanada, T. Ogino, S. Ohno, K. Watanabe, K. Nakano, T. Morooka, M. Oka & K. Kobayashi

## Educational Use of a Tablet PC by a Student with Multiple Disabilities

I. Kobayashi & N. Tanaka

This report describes the educational use of a Tablet PC by a student with multiple disabilities.The student was a 9-year-old girl with physical, intellectual, and visual disabilities. At school, she had two educational needs to improve.motion control of fingers and handsmaintaining visual attention on objectivesWe tried an educational program for using a Tablet PC for 6 months. One program was about an hour. In a program, several applications were shown in order. The student then attempted to operate them. The educator responded to the action of the student or application. Sometimes the educator assisted the student’s operation.Analysis of video recordings showed improvements in two of the student's educational needs. The results implied educational effects of using a Tablet PC for students with multiple disabilities.

## Understanding Factors Influencing Challenging Behaviours among Children with Autism Spectrum Disorders (ASD) and Multiple Disabilities (MD)

C. Kwek, B. Lee & J. Teng

Examples of challenging behaviours:
Hurting oneself and/or others
Repetitive behaviours such as flapping of hands,
rocking Uncontrollable tantrums which include crying and screaming

Several factors have been found to affect challenging behaviours among children and young people with Autism and Multiple Disabilities. Age, gender, Intellectual and Developmental disability, are just some examples. There is also a need to find out what increases or decreases challenging behaviours in children and youth in a special school in Singapore. This will help us understand and manage their behaviours better.

AWWA school has 134 pupils with Autism and 126 pupils with Multiple Disabilities. They are aged between 7-18 years old. We will be using a survey called the 'Developmental Behaviour Checklist’ to find the factors that affect challenging behaviours among these pupils. The survey will be given to 84 teachers who will answer questions about pupils from their class.

Answers from the survey will help us find out what increases or decreases challenging behaviours among our pupils. This will give us a better understanding of our pupils. We will then be able to help them better by using the right methods to manage their behaviours.

# A study on experience of parents for the transition to middle school of students with autism spectrum disorder

W. Lee, S.C. Kwak, H.J. Kim & M. Shi

## The Impact of Sensory Issues on Children on the Autism Spectrum in Mainstream Classrooms: Teachers' Perspectives and Training Needs

P. Molteni, L. d'Alonzo & M. Colombo

We investigates how much teachers are able to understand the needs of a student with autism and his/her sensory sensitivity.

This research analysed:
- How primary and secondary school teachers' understand autistic sensory perceptions?
- What is the impact on classroom inclusion and learning of sensory diversity?
- Which are the teachers' training need on sensory stimulus?

We answered these questions through 133 questionnaires and 6 focus groups.

We found out that:
- Teachers are not able to recognise sensory issues of autistic children;
- Teachers with no specific training don't recognize the student's needs on sensory perceptions;
- Hearing and sight issues have a big impact on learning skills.

We discovered that is very important to understand autistic sensory issues and teachers need to be trained to be able to do it for supporting the student's quality of life at school.

## Differences in behavioral evaluations for boys with ADHD and/or PDD between parents and teachers with reference to the child's age

T. Morooka, Y. Kado, A. Takeuchi, K. Hanafusa, M. Oka, T. Ogino, H. Yoshinaga & K. Kobayashi

## Handwriting in Children and Adults with Down Syndrome: Is My Handwriting so Different?

E. Moy, T. Tsao & C. Tardif

Handwriting is needed everywhere, at school or at work, where inclusion is important. In this study, we want to know how people with Down syndrome write, compared to typical people:Is it of the same quality, the same legibility?Is it slower or faster? The BHK test is used here to answer those questions. Each of the 23 participants with Down syndrome (aged from 10 to 40) has copied a text for 5 minutes. A score of handwriting quality is calculated with 13 criteria and the handwriting speed is measured by the number of letters written in 5 minutes. As the years go by, handwriting is improved in quality and speed. However, adults with Down syndrome of this study have shown a lower quality and slower handwriting than typical adults. Those results should be completed by an analysis of handwriting with a graphic tablet to understand the movement dynamic during handwriting.

# Physical Exercise Program Using Tablet PCs for Maintaining Exercise Volume in Students with Intellectual Disabilities

K. Odaka & I. Kobayashi

In this study, we introduced and assessed a physical exercise program using Tablet PCs. The aim was to maintain adequate exercise volume for students with intellectual disabilities (ID). Three students with ID participated. They received instruction of the program at school. After they returned home, they exercised by viewing video lectures on a tablet PC. Calorie consumption and active mass were recorded using an activity quantity meter. We compared average values of the following two conditions.
Condition 1: Days when participants exercised with a tablet PC.
Condition 2: Days when participants did not exercise with a tablet PC.

All participants were able to exercise with tablet PCs independently with no trouble. Numbers of calories consumed and active mass were higher for condition 1 than for condition 2.

Results underscore the effectiveness of tablet PCs as health-care supporting tools for students with ID.

## The effectiveness of the T.Jacket for children with autism spectrum disorders

K.K. Poon, I. Chew, A. Tan & J. The

## The inclusive college experience: benefits, challenges and outcomes experienced by students with IDD

S. Ryan

## The effect of contact frequency to people with intellectual disabilities on attitudes

M. Saito, Y. Okabe, Y. Ozaki & G. Toth

## Self-concept of pupils with learning/intellectual disabilities in regular primary school

M. Schmidt Krajnc, A. Prah & I. Schmidt

## A Support System for Differently-Abled Learners in General Education

A. Sentones

The study suggests forming a team to help out special learners in general education classes. The team is composed of the following: Principal, Assistant Principal, Guidance Services, general education teachers and teachers with training in Special Education. A meeting was first done to find out how to assist special learners in school. This was followed by a one-on-one talk with the members of the team. The answers were used to put up a structure that teachers can use to help these learners. This is what the speech is all about. Results from the interview and group talk show that teachers are open to helping out these learners. The study talks of a school structure for teachers to use to help special learners in general education classes.

# Literacy and Numeracy in an Aging Population of Individuals with Intellectual and Developmental Disabilities

C. Shivers, M. McCarron & P. McCallion

Many people with intellectual and developmental disabilities have trouble reading, writing, or understanding numbers. These troubles can make it hard for them to complete activities such as shopping or taking the bus. We want to find out how many older people with disabilities have trouble with words and numbers. We spoke to people with disabilities and their carers, and we asked them if they have trouble with: ReadingWritingUnderstanding numbersUsing money If they said “yes," we asked them more questions about what kind of trouble they have. We spoke to these people twice – three years ago, and again last year. Most of the people we talked to did not have a leaving certificate from school, and most of them told us that they have some kind of trouble with reading, writing, numbers, or money. Even though they had troubles, most of these people did not take classes that could help them understand words or numbers better.

## The Socio-economic Status of Parents and Access to Inclusive Education for Children with Mild Intellecutal Disabilities

G. Szumski & A. Firkowska-Mankiewicz

We have gathered a lot of information about 13 year - old children and we came back to them when they were 36 years of age. We have found that to be successful in life - eg. to have good job and income - it is important to have better off parents, to be healthy in childhood as well as to be smart and motivated to learn. For to be satisfied, to have good quality of life - good health and better off parents is enough.

## Trial Production of Japanese-Version Multi-sensory Stories for Children with Profound Intellectual and Multiple Disabilities

M. Takano & M. Udo

Multi-sensory stories, which we can touch, hear, smell, look at and feel, fit for telling stories to children with profound and multiple disabilities. The reasons are... they can make those children aware of the world through the five sensesthey can make those children share attention with a storytellerSuch storytelling approaches are widely used in the UK and another European countries. To provide various activities for children with special needs in Japan, we have been trying making Japanese versions of multi-sensory stories. The aims of this session are...
to show some modified multi-sensory stories
to discuss strategies
to apply such stories to different cultures and the effects that could have

We made Japanese version multi-sensory stories which had characteristics related to their own language and culture. Attention to the pages and motivation for participating in the activities significantly increased during the trial. We concluded that multi-sensory stories modified to fit their culture could be a fun way for children to widen their world.

# Evaluation of a New Method to Remediate Time Processing Ability in Children with Intellectual Disability (ID) in Special Schools

S. Wallin Ahlström & G. Janeslätt

Aims: A new method “My Time"⍰ was evaluated. Could children with ID get better in daily time management and in autonomy when training with "My Time"?

Method: Classes in 8 special schools were lotted to training or control group. Children with ID aged 10-17 participated. Training with “My Time” means measuring how long time different daily activities takes to do. Time was measured in quarter-hour units “dots", using a special timer. Also training to remember how many dots (for how long time) each activity lasts. The classes trained for 8 weeks. Data was collected before and after training. Instruments were Kit for assessment of Time-processing ability (KaTid), Self-rating of autonomy and Time-Parent scale. Data was analyzed with statistical analysis.

Results: The training seem to be efficient (Effect Size: Cohen´s d 0.53). Preliminary results show better daily time management for the group training. In control group there was an increase in autonomy only during training.

Conclusions: Children with ID get better in daily time management when training with My time. The parents thought so too. To measure how long time different daily activities takes to do did help children to understand time better.

## The Support for Autistic Child's Unbalanced Diet

K. Yamane & Y. Fujii

The support for autistic children's unbalanced diet. Some Autistic Spectrum Disorders have strong unbalanced diets. We tried to make a special lunch for the children at our child development support center. After that their unbalanced diets improved. We analyzed 15 ASD children whose unbalanced diets improved. And we put them into four groups below:
Group 1 – By changing food into favorite textures, tastes, and colors.
Group 2 – By cutting food into favorite shapes, imitating family recipes.
Group 3 – By offering the same recipes or continuing what was already being eaten, and encouraging new food.
Group 4 – By controlling environmental stimulation.

Results:
Group 1 – 3 children: severe intellectual disability, oral hypersensitivity
Group 2 – 4 children: moderate intellectual disability, severe restricted imagination
Group 3 – 5 children: developmental age is over two, visual performance is dominant
Group 4 – 3 children: attention deficit disorder

We continued to offer 49 children this special diet for 8 years. 18 children could eat all of their lunch and 25 children could eat some vegetables. We should discover the types of individual characteristics early. And we would like to offer the special diet for children and their families.

## Young people with an intellectual and developmental disability and cleft lip/ palate: Self-perceptions and experiences of cleft treatment.

A. Bates, R. Forrester-Jones & M. McCarthy

Some people's faces are different because they were born with a gap in their lip/hole in their mouth. Some people look different and also have a learning disability. But researchers haven't asked them how they feel. There might be problems for people who look different and have a learning disability.

Who did I talk to?
I talked to 16 young people aged 9 to 14. I also talked to their parents and to health care staff. We talked about how people felt about the way they looked. We talked about young people's friendships and school. We also talked about the treatment they had in hospital.

What did I find out?
Looking different and also having a learning disability can be stressful. Hospital staff would like some training about how to make services better for people with learning disabilities. It is important to think about support, training and hospital care if you have a learning disability and a cleft.

## Functional behavior analysis as a diagnostic instrument for adults with profound intellectual disability and traits of obsessive-compulsive-behavior: a case study

C. Delgado, R.G. González-Gordon, J.I. Navarro & C. Bauer

## Structured Feedback from Older Adults with an Intellectual Disability on their Experience of Attending for a Health Assessment – Results from a Pilot Study.

E.A. Burke, M. McCarron, J.B. Walsh & P. McCallion

This study was to see how people with intellectual disability felt about doing health assessments as part of research. We asked people with ID and professionals about the best assessments to use. We also asked the group if the information we were giving people was easy to understand. We also asked them if the way we were explaining the assessments was easy to understand.

We then asked people with ID to volunteer to do the assessments and tell us after:
How they felt about each of the assessments
If the information was easy to understand
If there was anything that could be done better

People were happy to take part. They told us that the assessments were easy to do and none of them hurt.
They told us some things that would help to make doing the assessments better for others, like making the pictures bigger or to show people what to do in case they could not read.

They felt that all the assessments were fun to do and easy to understand.

### Evaluation of a guided self-help package for people with intellectual disability

E. Chaplin, T. Craig, J. McCarthy & N. Bouras

### Home visits: a reflection on family contact in specialist forensic learning disability care

L. Cheshire, V. Chester, F. Esan & R.T. Alexanderâ

### What do New Zealand paediatricians say about services for young people with a dual diagnosis?

P. Clark & P. Reed

### Supporting empowerment processes in women with intellectual and developmental disabilities

B. Cytowska & E. Zierkiewicz

### Interventions for autistic catatonia: a systematic review

H. DeJong, D.J. Hare & P. Bunton

## Exploring familial perspectives on parental bereavement in individuals with intellectual disabilities

L. Douglas, S. Guerin, J. McEvoy, K. Lockhart & P. Dodd

We would like to find out how families look after people with intellectual disabilities when their mother or father dies. We will interview family carers about their experiences caring for their family member with intellectual disabilities, following a death in the family. We will ask them to answer a list of questions about how their family member with intellectual disabilities coped with the sadness of losing their mum or dad. This list is called the 'Complicated Grief Questionnaire for Intellectual Disability' (Guerin et al., 2009). Some people with intellectual disabilities do not understand what dying means. It is important that people with intellectual disabilities go to the funerals of their loved ones because if they are not allowed to go, they might be sad for a long time and might be difficult to care for afterwards. However, going to funerals might be really hard for people with intellectual disabilities if they do not understand what is happening and why. This study will find out how people with intellectual disabilities deal with the death of their parent, from the point of view of their family carer. This information will then help doctors to help other people whose mother or father dies.

# An Effective Falls Group: Working with People with Intellectual Disabilities

B. Flood, J. Flood, M. O’ Sullivan, G. Bourke, C. Mug & J. Connolly

People with intellectual disabilities can fall. Falls can cause injury, pain or broken bones. It is important that everybody working with people with intellectual disabilities tries to stop falls happening.

In the centre where this project took place,
the pharmacist,
the physiotherapist,
the pccupational therapist,
the dietician,
the activity manager,
the nurses
worked together in a falls group for years to stop falls happening. The number of falls and fractures went down. The falls group was effective.

## Cardiometabolic health in students with intellectual disabilities attending schools with a general health policy

E. Flygare Wallén & C. Marcus

We wanted to know if healthy habits during school hours could affect students' health. A general health policy means here:
Being more active physically
Eat less unhealthy food
Eat more fruit and vegetables
Cardiometabolic health is the health of your heart and blood vessels.
One way to measure health is to measure your body weight. Being overweight can be bad for your health.

We measured 120 students, age 16-22, all with mild to moderate intellectual disability. We measured weight and height. We measured waist and blood pressure. We drew blood samples. The measures were taken in the beginning and in the end of a school semester (January and May). We found that many students were overweight. We found that after one school semester at these schools: Students did not get more overweight. Students' waist got a little bit smaller. This could be good for your health. To attend a school with healthy habits seems to be good for your health. But more studies need to be done.

## Factorial structure of the health promoting lifestyle questionnaire-II in a sample of direct support professionals of adults with intellectual and developmental disabilities

J. Gray & B. Riley

## Aging and intellectual disability in S~ao Paulo, Brazil

L. Guilhoto, R. Leondarides, L. Castro, S. Sena, C. Almeida, D. Karmeli, E. Macedo, J. Righini, A. Alves, E. Tarandach, M.F. Prezia, V. Faria & E. Cavalheiro

## The prevalence, topography and operant function of challenging behaviour in fragile X syndrome

R. Hardiman & P. McGill

## Preliminary results from the Dementia in Down's Syndrome study: Imaging beta-amyloid in the brains of adults with DS using [11C]-PiB-PET.

T. Annus, L.R. Wilson, S. Zaman, Y. Hong, T. Fryer, J. Coles, F. Aigbirhio, R. Smith & A. Holland

Aims:
People with Down's syndrome (DS) have a high risk for memory problems and Alzheimer's disease (AD) as they get older. We want to understand if this AD is caused by a chemical called amyloid, in the brain, where it is and how much there is in the brains of people with DS.

Methods:
Forty-two adults with DS aged 25-65 had an MRI and a PET brain scan using Pittsburgh-Compound-B (PiB). Dementia was assessed using CAMDEX-DS questionnaire.

Results:
Most people with DS older than 50 years showed amyloid in their brains. Older people had more amyloid than younger people with DS. Participants with dementia had more amyloid than participants without dementia. Most amyloid was seen in striatum in the brains of all participants.

Conclusion: The older people with DS get, the more amyloid they have in the brain. We believe that amyloid build-up might begin in the striatum in DS, which has shown to be true for people with other genetic forms of AD (Klunk et al., 2007; Koivunen, et al. 2008).

## Correlations between Motor and Cognitive Development in Children with and without Developmental Disabilities

S. Houwen, L. Visser, A. van der Putten & C. Vlaskamp

We know that movement activities are good for helping children to do other things such as thinking and talking. We want to learn if movement activities are also good for thinking and talking in children with developmental disabilities. We used an instrument which can measure how well a child can talk, how well a child can move and how well a child can learn and understand things. We did this test with many children with developmental disabilities and children who do not have developmental disabilities. The speech will be about the results of this instrument.

# Do people with a learning disability know what healthy eating is?

S. Harris, D. Lomas, M. Perkin, G. Gallagher, R.W. Williams, S. Nash, J. Huws, A. Green, F. Waddington & J. Payne

Aims:

The 'Question-Aires' is a research group funded by the Welsh Government's Learning Disabilities, Autism, and Neurodevelopmental Network and Involving People. We are people with a learning disability, volunteers, staff from Bangor University, Conwy Connect and Mencap Cymru. We do research that people with learning disability want to do on topics that are important to people with a learning disability. This study looks at the views that people with learning disability have about healthy eating.

Methods:

The group have developed questions about healthy eating. These questions have been checked with people who were at a conference for people with learning disability. We have received ethical approval to do our research and have asked adults with learning disability living in North Wales to take part in the research.

Results:

The findings will show what people with learning disability know about healthy eating, if they eat healthily, and what needs to be done for them to eat healthy foods.

Conclusions:

The findings will be shared with those taking part in the study, other people with a learning disability, and with people who are involved in providing care and writing guidelines about healthy eating.

# The increased use of short-term care facilities by people with PIMD (profound intellectual and multiple disabilities) requiring medical care

Y. Iwasaki, M. Suzuki, H. Horie, T. Masuyama & M. Arima

People with PIMD at home are becoming to require more complex medical care in Japan.

This study is to find:
The trend of the needs for short-stay services in the community.The types of medical care that are necessary for them.Varied conditions among the users of short-stay service at TMTMC were analyzed between 2006 and 2012.

The findings are:
266 people used respite care service in 2006.The number increased to 664 in 2012.
The most common reason for using the service is temporal relief from care giving.
Users of mechanical ventilators increased from 25 to 224 by 2012.
Medical needs of people with PIMD are expected to continue growing.

It is significant to have enough respite care facilities in order to meet the needs of such people.

## Low-dose venlafaxine for behavior problems in adult patients with pervasive development disorders and intellectual disabilities

M. Kosel, L. Peyruchaud, B. Fallevoz, D. Caharel, M.-C. Traoré & G. Galli Carminati

## A cognitive-behavioural emotion management group for people with intellectual disability

M. Kosel, L. Peyruchaud, B. Fallevoz, D. Caharel, M.-C. Traoré & G. Galli Carminati

## Mixed socio-educative and psychiatric therapeutic living structure for patients with autism spectrum disorders, intellectual disability and challenging behaviour

M. Kosel, L. Peyruchaud, B. Fallevoz, D. Caharel, M.-C. Traoré & G. Galli-Carminati

## Trauma in people with intellectual disabilities

B. Lueger-Schuster, S. Maxian & A. Kocman

We know very much about trauma in the general population.

However, there is not much research and knowledge about trauma in people with ID. That is why we suggest some starting points for research:

It would be good to take a closer look at specific vulnerabilities of people with ID and how they react to traumatic stress.

In this poster, we are summarizing how trauma should be assessed in people with ID.
This is very important, because people with ID seem to be at greater risk of trauma and post-traumatic stress disorder.

Many people with ID have problems to express themselves.

That is why trauma and post-traumatic stress disorder is still often unrecognized.

Sometimes it is misattributed as challenging behavior.

Furthermore, we are discussing possible treatments for people with ID who experienced trauma.

## Drug therapy in adult/elderly people with intellectual disabilities: results from a multi-centre sample

U. Mantesso, L.P. De Vreese, M. Bertelli, E. De Bastiani, E. Weger, A. Marangoni & T. Gomiero

## Drug therapy in adults/seniors with Down Syndrome: results from a multi-centre sample

U. Mantesso, L.P. De Vreese, M. Bertelli, E. De Bastiani, E. Weger, A. Marangoni & T. Gomiero

## Bereavement Support for Adults with Learning Disabilities

V. A. Mason

We need to understand how people with learning disabilities are supported when someone they love dies. Support workers are the best people to help us understand how this happens, but they don’t have a voice in research. A PhD study is employing some support workers to do some research into how bereavement support is done. These support workers are running some small groups for participants to talk about how they do bereavement support with people with learning disabilities. This poster looks at how working with support workers as researchers happens. It will talk about how the support workers were employed, what skills they have and what experience they brought to the research. This poster wants to show that support workers should be seen as useful to research and not a problem.

# Examining the Usefulness of Measures of Executive Function in Individuals with Down's syndrome – A Comparative Review

E. McGlinchey, M. McCarron & P. McCallion

There are a lot of studies that measured Executive Function in people with Down’s syndrome. We wanted to compare the measures used in all of the studies to find out which ones were used the most and which measures were best for measuring executive function in people with Down’s syndrome. We searched for all of the studies that examined executive function in people with Down’s syndrome using PUBMED, CINAHL and Web of Knowledge. From reading all of the literature, we found that executive function is a term that is used to describe actions such as planning, solving problems, switching tasks and planning. It is the front part of the brain that is active when doing these tasks. Studies have found that it is good to use a lot of different tests to measure executive function. So far, the Weigl Card Sorting Test, the Tower of London, and the Stroop test were the measures most often used. A lot of the same measures were used in different studies. Studies have started using computed versions of these measures in the general population. We need to find out more about using computer versions of the measures for people with Down’s syndrome.

# Cognitive Reserve: Implications for Research in Dementia for people with Down's syndrome.

E. McGlinchey, P. McCarron & M. McCallion

We wanted to find out how the theory of cognitive reserve will help us in the future to learn more about dementia in people with Down’s syndrome. To do this, we did a literature search to find out what information was already out there. There are a lot of different databases to search on, but we used PUBMED, CINAHL and Web of Knowledge. We looked up the words 'Cognitive reserve’ Down’s syndrome’ and 'Dementia’. We read the description of the articles and picked the ones that were most relevant to us. Cognitive reserve explains how the brain can suffer damage or disease without the person showing signs of that disease. In some people, for example, a brain scan will show that their brain looks like it has dementia, but the person won’t act as though they have dementia. We should explore this theory in relation to people with Down’s syndrome and dementia to see if it will help us to learn more about delaying dementia and to give better care to those who have dementia.

## Impact of motor and intellectual impairment on activities and participation of patients in institution for children with orthopedic impairments in japan

T. Mita, F. Mikami & K. Mita

## Relationships between physical and mental health and challenging behavior among people with intellectual disabilities

D. Morin & J. Mérineau-Côté

# Intellectual Disability and Dementia - Perception of Symptoms and the Management of Progression of Dementia by Staff of Group Homes for People with ID

V. Nartschenko & C. Gärtner

Aims: People with intellectual disability are getting older and have as all people of old age, a risk of becoming dementia, which is a disease of the brain. For Germany it will be the first time in history to deal with older people with ID.

Method: The staff of group home care settings has therefore to take care of all issues which come along with a dementia. To get more information about the disease the staff of three German residential facilities for persons with ID has been asked to fill out a questionnaire. In this survey different questions have been asked about the behavior of people with intellectual disability and a dementia.

Results: We found out that people with an intellectual disability and a dementia often show strange behavior. We also found out that the staff needs more information and continuing education about the disease.

Conclusion: Nursing homes do not fulfill the needs of people with ID and dementia. Special caring programs for people with intellectual disability and dementia have to be developed in order to allow the person to stay in their accustomed environment.

# How Tracheo-esophageal Diversion and Laryngotracheal Separation Improved a Case's Quality of Life

H. Ozawa, Y. Nomura, K. Amemiya & Y. Ozawa

Aims: We introduce the improvement in a case of PIMD by tracheoesophageal diversion and laryngotracheal separation with the help of social services.

Method: A girl was born at a weight of 666g in 25 gestational of age. She had mechanical ventilation for Respiratory Distress Syndrome. She stopped the mechanical ventilation on 191 days. After that time, she stopped breathing and changed facial color to pale when crying. So she had tracheostomy at 2 year-4 month old of age. Her parents wanted to take her home, so she was discharged at 3 years old. But she was re-admitted to hospital due to repetitive aspiration pneumonia.

Result: She was operated on for tracheoesophageal diversion andlaryngotracheal separation. After that, her condition improved and she haslived comfortably with the help of social services.

Conclusion: She smiles everyday with her family. It is important to ensure that with the help of social services she has a happy life.

## Healthcare use, ill-health and mortality in adults with intellectual disabilities (ID) and mealtime support needs

C.M. Perez, S.L. Ball, A.P. Wagner, I.C.H. Clare, A.J. Holland & M. Redley

About 1 in every 6 people with intellectual disabilities needs help at mealtimes. Most of these people have problems with eating, drinking or swallowing. We do not know enough about how these problems affect their health.

We talked to 142 people with intellectual disabilities and their carers. They spoke to us two times, one year apart. All of the people with intellectual disabilities needed help at mealtimes. Looking at a one year period, we were interested in:

- How often each person saw the doctor
- How many serious health problems each person and
- How many people with intellectual disabilities died.

Almost all of the people who took part saw their doctor at least once a year. Chest infections were the most common health problem. About 1 in 3 people had chest infections. These infections were sometimes very serious.

Eight people died in one year, or 5 out of every 100 people. All of these people died from a chest infection.
More people died than we expected.

We think that people like doctors and carers should pay more attention to health problems related to eating and drinking.

# BEAT-IT: A randomised controlled trial comparing a behavioural activation treatment for depression in adults with intellectual disabilities with an attention control.

E. Scott, A.G. Jahoda, C. Melville, R. Hastings, S. Cooper, A. Briggs, D. Dagnan, A. McConnachie, C. Hatton, C. Williams & R. Jones

Many people with intellectual disabilities feel low and have depression; there isn’t much information about what helps these people get better. There are two talking therapies that we think might help. Over one hundred and sixty people across Scotland, England and Wales will take part in the study. Half of the people will get 'Behavioural Activation’ therapy and the other half will take part in guided self help. Behavioural Activation is all about helping people do more of the things that they enjoy. Guided Self-Help uses booklets about sleep, problem solving and activity to think about the person’s low mood.  Everyone involved has 8-12 sessions, over 4 months with a therapist (a nurse or occupational therapist that has been trained in the therapy) and a support person. A researcher visits the person to ask them questions before therapy, after therapy and then 8 months after they started therapy and 12 months too. We will look at whether people say they feel any different after therapy in terms of their depression. We will also see if there is any change in their anxiety, quality of life and how much activity they do.

## Raven's Coloured Progressive Matrices: A useful tool to match adults with Down syndrome and controls?

C. Straccia & K. Barisnikov

We need to compare adults with intellectual disability of different causes in order to provide to health professionals information about the behavioral characteristics of each cause. These comparisons require measures to select groups with the same level of ability. One of those measures is called the “Raven’s Coloured Progressive Matrices". This poster presentation is about the application of the “Raven’s Coloured Progressive Matrices" to select groups of adults with Down syndrome. The results of this study show that adults with Down syndrome made the task in the same way of another group of adults with intellectual disability. This means that the “Raven’s Coloured Progressive Matrices" is a good tool to study the behaviors of adults with intellectual disability of different causes.

# Kinematic Features of Spatial and Temporal Aspects in Individuals with Intellectual Disabilities during Continuous Limb Movement

H. Suzuki & M. Ushiyama

We need information about motor performance of individuals with intellectual disabilities (ID). For example : If tasks are more difficult, how the performance would change.We asked participants to beat two wooden plates alternatively with a stick.We got the following stick movement variables;Mean movement time (second)Peak height (cm) We found out that the perfomance changed both in individuals with and without ID. However, the way to perporm were similar. This results means that longer trajectory of the stick would be used to correct the movement under difficult situation.

## Effectiveness of Antiepileptics for Behavioral Symptoms in Persons with Severe Intellectual Disabilities using a Severe Behavioral Disorder Assessment Scale

K. Taniguchi, K. Kamino, T. Kudo, H. Tanimukai & M. Takeda

We have evaluated the effectiveness of antiepileptic medication for the behavioral symptoms in adults with severe intellectual disability.

We need information about: Which antiepileptic is effective for behavioral symptoms? What kind of symptom should we prescribe antiepileptic for? We scored the extent of the behavioral symptoms in 80 cases using a severe behavioral disorder assessment scale. This scale rates the frequency of 11 categories of behavioral symptoms. We calculated correlations between the dose of 3 antiepileptics and the score of a severe behavior disorder assessment scale. valproic acid, carbamazepine, and phenytoin

We found out that while valproic acid was effective for the obsessive/hyperactive and self-injurious behavior, phenytoin was rather effective for the aggressive behavior.

## An assessment of state regulation in children with attention deficit hyperactivity disorder and pervasive developmental disorder

Y. Tsushima, S. Sanada, S. Ohno, M. Oka & T. Ogino

## Launching the international society of cancer and intellectual & developmental disabilities (ISCIDD)

I. Tuffrey-Wijne, D. Satgé, B. Azema, J.-B. Dubois, D. Willis, G. Santen, S. Parish & H. Van Schrojenstein Lantman-de Valk

## A cross-sectional study on relations between motor dexterity and sensory functions of elementary school children in Japan

M. Ushiyama

Why are recent school children becoming clumsier than before? I have no clear answer to this question. So, I conducted a survey to find out the following points:
Whether or not motor dexterity and sensory function are related.
Whether or not clumsiness could be improved, as children are growing upIs there any difference between boys and girls?

I asked parents to fill a questionnaire on: Children's attributes (e.g. sex, grade)
Conditions on motor dexterity and sensory functions

Results suggested:
Children, who tended to have hyper- or hypo-sensory functions, would have less motor dexterity
As children grow up, clumsiness could be improved
Boys would be clumsier than girls

# Developing a new digital diagnostic instrument for social information processing in youth with externalizing behavior problems with and without mild to borderline intellectual disabilities.

M.M. van Rest, M. van Nieuwenhuijzen, A. Vriens, C. Schuengel & W. Matthys

We need to have information about why children have problems in their behavior. Perhaps it is because the children experience difficult social situations. They think different than others about the situation and the people in it, and they react angrily. We call that social information processing. To collect information about social information processing we need a new test. We developed this new test, called the SIP-test, and we will show the first results. Test materials, like videos, were developed for children. Then, we could test: their reactions to social situations, how well they could recognize emotions, and how well they could keep their attention or remember things. We tested many children and adolescents with the new SIP test. We found that the new test worked well. We could see angry reactions of the children to the videos. We found that children with intellectual disabilities recognized emotions less well than other children. Their attention and their memory was less strong than that of other children. This test can now be adapted to a second, better version. We can use that version to test many more children with problems in their behavior.

## Development of an intervention for children with a mild intellectual disability of parents with a mental illness (COPMI)

I. Riemersma, F. van Santvoort & I. Vermaes

## Monitoring health in people with intellectual disabilities: some implications for the integration of health and social care

D. Willis

## Living in the Community

### Practical Study of the Effect of a Sibling Support Program Creating a Picture Portfolio about a Child with Disabilities and a Family

M. Abe

Siblings of children with disabilities need a support program to address their problems. So we made a program to create a picture portfolio. It helps siblings understand for their brother and sister with developmental disabilities and their family. 7 siblings from 7-11 years old participated in the program. They had a brother with ASD or intellectual disability. The contents of the program were as follows:

(1) Playful movement activities
(2) Discussion and learning about their brother's disabilities
(3) Creating a picture portfolio about their brother with developmental disabilities, their family and themselves

After the program, we found the following results:

(1) In the interview, siblings' appropriate answers about characteristics of disabilities increased. They got to know how to deal with their brother's behavior problems.
(2) In the questionnaire, siblings' negative feelings and concerns about their brother with disabilities were reduced. "Future concerns" and "Hyperresponsibility" decreased significantly.

We found out this program was useful in improving the problems of siblings.

# Eight years later. Long-term follow-up of former inpatient survivors of institutional abuse

J. Bernall & R. Shankar

## Cost and Benefits of Social Care Support for Ex-offenders with Intellectual Disabilities

P. Chiu, P. Triantafyllopoulou & G. Murphy

We were unsure of how much support people with intellectual disabilities (ID) gets when they leave prison, and if the support offered were helpful for the person.

We worked with men with ID who have just left prison, and their care managers / probation managers, for 1 year.  We carried out two interviews with each man to look at their:
Friendships (social network)
Use of support services
Quality of life Health and well-being
Any risky behaviours / re-offending

We also checked with their care manager or probation manager with:
The support services offered
Anymore offences occurred

For each man, we carried out the interview at one month after leaving prison, and at nine month's time.

So far, we found out there was a varied range of support services for men with ID, who has just left prison. In most cases, support systems were not fully set up during the first month of the men leaving prison. Families played a big part in the men's social network, but they did not always provide helpful support.

The project suggests many men are not well supported when they leave prison and are at risk of re-offending.

## Adolescents with intellectual disabilities who commit sexual offenses: exploration or exploitation?

V. Cruz

## Characteristics of High-cost Residential Placements and Implications for Local Community Support

R. Deveau, P. McGill & J. Poynter

What is this poster about: We collected information from workers in local government and health service districts in part of England, about the 5 people with intellectual disabilities in each district who needed the most money to provide their care. We asked how much their care costs a year and about their needs. We collected information on 105 people all together.We found that the average amount of money needed was £200,000 a year, the lowest was £81,000 and the highest £430,000. Many of these 105 people were cared for away from their families, friends and local communities. Many of these people showed behaviours that staff find difficult to manage, had mental health problems, they may have broken the law and been to court, had lived in residential school and away from their families as children and now lived in hospitals, often with locked doors. We decided that more early help should be provided to families and people with intellectual disabilities, especially when they are children, to help them live with or near families and friends in their local communities.

# Evaluation of a model of positive behavioural support in a challenging behaviour care pathway for adults with intellectual disability aimed at community intervention

S. Horsley, D. Wright, J. Blake, S. Sivell & S. Zahid

## Communication Access: A Pathway to Community Inclusion

H. Johnson, B. Solarsh & D. West

Aims:

We are working on a way to make sure everyone can get their message across when they are in the community. This is called communication access.

What we did:

Scope has a checklist to measure how well staff communicate in different places. We help shops and services to become communication friendly. We then go to that place and check how well staff are doing. We also check how well staff communicate on the phone. Places that do well get the communication access symbol to put up in their shop or service. This helps everyone to know which places they can use if they have communication difficulties.

Results:

More than 50 places have been checked and now have the symbol in their shop or service. Training people how to communicate is important

Ending: It is very important to make sure people who have difficulties with speech and understanding can get their message across. More and more places are interested in this.

## The lived experiences of women with an autism spectrum disorder: a narrative inquiry

L. Kanfiszer & S.Collins

## Evaluation of the current educational situation of caregivers supporting people with intellectual disabilities

M.L. Gersch, L. Kascha, H. Perko & K. Stadlbauer

## Uniting forces: a new Dutch programme on research and knowledge transfer

M.C.O. Kersten, W.H.E. Buntinx, P.J.C.M. Embregts, H.M. Evenhuis & C. Schuengel

## Comparing the attitudes of health professionals and the general population towards people with intellectual disabilities

D. Morin, T. Lopes, A.G. Crocker & J. Caron

## The sibling booklet: talking with siblings about their experiences to enhance their sibling's quality of life

T. Moyson & M. Vrijders

## Without CAAPITT, it's Curtains to Accessible Information!

W. Oldreive & M.P. Waight

We have been looking at ways of making sure that people make good information for people with ID. We think that there are 7 things that people need to think about:

Control e.g. the person can use the information source such as turning over book pages, or switching on a computer
Accessibility – the person can understand the information and use it
Availability – the person can get information they need
Personalised – the right information for the person
Inclusive – everything the person needs is brought together
Timely – it happens at the right time
Targeted – the information meets the person's needs.

We have called these the CAAPITT principles. The poster will look at these ways of helping people, talk about them and give some examples of how they work.

## Adults with Intellectual Disabilities: A Look at Spain and Chile

A. Pala

There needs to be a better understanding of what opportunities adults with intellectual disabilities have in Spain and Chile. Also we need to better understand how adults with intellectual disabilities feel about society and how society feels about them to increase feelings of inclusion into the community. To do this I:
talked with people at organizations that work with adults with intellectual disabilities and watched what they did there.
interviewed/surveyed individuals with intellectual disabilities, people that work with them and also family members.
gave a 5 questions survey to random people in a public place that asked questions like “Do you think people with intellectual disabilities should be included in society?” or “What are five words that come to mind when you think about an intellectual disability?”

I did this in both Spain and Chile and found that society wants to include people with intellectual disabilities, but sometimes do not know how so they seem like they do not want to. The public needs to be educated better about people with intellectual disabilities.

# Promoting Family-centered Practices in Early Intervention Centers for Children with Intellectual or Developmental Disabilities

C. Simón, M.T. Pró, M. Dalmau, R. Vilaseca, F. Salvador, D. Izuzquiza, A.L. Adam & N. Baqués

We are working with families as a team, taking their choices into account, responding to their needs, and working in natural contexts (their house, schools, etc.) to improve early intervention for children with intellectual disability.Traditionally in Spain we work more focused on the child than in their families and many people know nothing about this second way of working. This is what we tried.

We asked some teams of professionals to try to support children using this new approach. We proposed them to follow the next steps: Seeing the needs and the wellbeing of the families, asking with which families were going to work in this special way for the first time and working with these families in this special way.

We asked the families to go to their homes. We asked how happy the families were with the daily life activities and with the way their children acted, participated and communicated during them.
Also, we asked families what they thought they could do in order to improve these activities and, also, to solve out their main worries. The professionals went back to the homes, if possible, to see how things were going, and to support families' work.

At the end we checked if these families had improved their general well-being. This special intervention was not always easy. However, the experience helps us to understand what can be done to help teams to apply it and improve their work with children and families in this way.

# Needs Analysis and Future Development of Profound Intellectual and Multiple Disability (PIMD) Daycare Services in Japan

S. Suemitsu & S. Murashita

We considered that we should have to know about the needs in the people with profound intellectual and Multiple Disabilities (PIMD) who use the day care centers. For example we need information about:

- The needs for the medical support
- The needs for the support for activitiesin daily living.
- The needs for the support to the families.

In order to gain this information,we had carried out the survey by distributing a questionnaire forms to the guardian of PIMD who live in the community, and aimed to evaluate what kind of healthproblems they have.
Questionnaire form is made up with 16 questions. It had distributed to 447 families with PIMD by direct mail and via care centers. 228 families (51.0%) have responded.

The findings are that
(1)needs for day care centers were shown by 65 % of respondents,
(2) 22% of respondents havehome visits care by visiting nurse and 28% claim to have a care by homevisiting care taker.

We found that complex medical care tasks, such as the daily usage of ventilators, tracheostomy or endotracheal intubation, nasopharygeal airway tubes and oxygen inspiration tasks are being undertaken by family members at present time.These findings indicated the needs of educating family member for an appropriate manipulation of these procedures for very emergency situation, beside to provide sound knowledge and skill to home bound nurse and care giver.

# Misunderstandings about Developmental Disabilities in Japan

Y. Tamekawa, S. Hashimoto, A. Hayashi & A. Kanno

In 2000, we made a website to support Japanese adults with developmental disabilities.The website has 95 questions. For example, the questions are about:communication, daily living, social activity, academic skill, leisure skill, working
Before answering these questions, users must fill in an online registration form.

For the last three years, 3469 answers were gathered. Of the users:
27% are parents of persons with developmental disabilities
21% are persons themselvesIt is an unexpected result that the website is used by persons themselves.

This does not mean that many persons with developmental disabilities can use computers and Internet. In Japan, many people have the misunderstanding that their own trouble is caused by developmental disabilities though they have no developmental disabilities. We should solve these misunderstandings.

## Self-determination: the right of all and for all

V. Vega, J. Benavente, M. Flores & J. López

## Parent Perceived Challenges to Treatment Utilization in a Publicly-Funded Behavioral Intervention Program

M.E. Yingling, R.M. Hock, A. Cohen & E. McCaslin

We need information about what makes it hard for parents of children with autism spectrum disorder to use a program that teaches their children living skills.

We need information about: What do parents think makes it hard to use the program for their children? Do different kinds of parents think different things are hard? What do parents think could make it easier for them to use the program? We made a survey to answer these questions. We sent it to parents by mail and email. The speech will be about this survey.

We found several things:
First, a child's school schedule and a child being too busy with other programs made it hard for most parents to use the program.
Second, the things that made it hard for only a few parents were family disagreement and how far away the program's services were.
Third, parents who were working outside of the home and who had children with lots of problem behaviors had a harder time using the program.
Fourth, single parents did not report as many of the hard things on the survey list.
Finally, parents told us what could make it easier for them to use the program.

# Emotional availability of support staff and attachment behaviour of young adults with mild ID and attachment problems

M.J.M. Boon, J.C. de Schipper & T. van der Wiel

## Testing Self-determination Tools for People with Intellectual Disability Reaching the End of their Lives

A. Dusart

We did research on end-of-life conditions for French adults with intellectual disability. We wanted to know if professionals who provide care for this population were interested by instruments which could help them in such circumstances. A call for practical instruments was sent around the word.

We received 10 tools to help people with ID who are seriously ill: to understand their condition and its outcome, to develop their preferences for end-of-life and make these wishes known. 6 tools were given to teams working in settings which support or care for seriously ill people with ID. Feedback provided information on the professionals' perception of these tools and how they felt the tools could be used. We received a range of quality ratings, recommendations for improvement, and changes suggested for making the tools more suitable in France.

Results also indicated that the teams were hesitant regarding these instruments. The tools demanded a more open dialogue with individuals who have potentially fatal diseases, than that to which the professionals were normally accustomed.

Nevertheless, discovering these tools provided the teams with new ideas and reduced their inhibitions about accompanying people with ID who are reaching the end of their lives.

## People with ID Growing Older: The Case for Specialist Care?

R. Forrester-Jones, D. Oliver & M. Barnoux

Aims:

People with disabilities are getting older and getting diseases like dementia. At the moment people with disabilities have little choice about where to go when they get old and sick. We looked at a small residential care home specially for people with disabilities who are old and need palliative care (end of life care).

Method:

We used a number of different types of questions to ask people who lived in the care home what they thought about their care. We also asked staff what they thought of the care home.

Results:

We think that this is the first care home in the South East of the UK to provide special care for people with disabilities who need palliative care. We found that people who live and work there think it is a very good care home.

Conclusion:

We continue to discuss whether or not we think it is good to have special care homes for people with disabilities who are older and need palliative care.

## Challenges Posed by Dementia in Everyday Working Life for Employees in Facilities for People with Intellectual Disability

U. Gövert, C. Wolff, B. Kuske, D.Specht & S.V. Müller

More and more elderly people with intellectual disabilities are living in institutions. Of these, some people suffer from dementia. In a dementia incease forgetfulness. We are interested in how forgetfulness changes the work of the employees. We asked 12 employees from 4 institutions. The employees work in different places.

We have found out:

- the employees need more time for the residents.
- the employees more often help residents.
- the environment hat to be conformed to the new situation.
- the employees wish new ways to support residents.

## Does participation in leisure activities influence the quality of life in children and adolescents with cerebral palsy?

M. Badia, B. Orgaz, M. Gómez-Vela & E. Longo

## Quality of Life in Children and Adolescents with Intellectual Disabilities

L.E. Gómez, M.A. Alcedo, V. Arias, A. Monsalve & Y. Fontanil

We need to know what aspects are important for children and adolescents with intellectual disabilities to enjoy a life of quality. For example, we need to know what things make them feel happy, what things they need to have, what aspects are important for their education, what kind of decisions and choices they are allowed to take, or what are the areas in which they need more support and help. Asking to experts in children and adolescents with intellectual disability and reviewing previous studies, we came up with a survey to assess quality of life. This survey is called the "KidsLife Scale". It is made up of 156 questions about the quality of life of a person. We asked these questions to professionals and relatives who knew well the person and we did this survey many times for many people with intellectual disability. We found out that the survey seems to be a useful tool to know what people need in their lives and how we can help them to get a better life.

## Occupational therapy supporting people with PIMD to engage meaningfully in activities at home

D.J. Haines, J. Wright & H. Comerasamy

## Communicative Means and Functions in the Degenerative Course of MPS III / Sanfilippo –Challenges and Chances for Managing the Communication Process

B. Hennig

Finding out about ways of communication in children with a progressive disease Children normally learn to walk, to talk and to communicate. They grow up to adults, living independent. But some children don't do so. After a while they stop talking again. Later they lose the ability to walk and they need assistance in all daily life situations. Some die before age of 20, some get 5-10 years older. The cause of that is a rare progressive disease, called Sanfilippo-Syndrome. At the moment doctors unfortunally can't promise any kind of cure.

It is difficult for the family to communicate without speech. It takes time to discover new ways of communication. But after some years parents and their children get experts in nonverbal communication.There is no book for parents how to learn this kind of communication. That's why a PhD student talked with more than 20 parents of a child with Sanfilippo Syndrome. By this way she collected many experiences about the communication process with children with Sanfilippo Syndrome.

The poster presents some of the results in summary.To share this information could be useful and important for other parents, but also for doctors and teachers.

## Autonomous goal setting in children and adolescents with ASD

S. Hodgetts, D. Nicholas, L. Zwaigenbaum, M. Stolte & S. Reynolds

## Knowledge transfer into society through an online toolkit on older people with an intellectual disability

M.C.O. Kersten & M. Hornman

# Diagnosis of Dementia in People with Intellectual Disabilities - A German Pilot Study

B. Kuske, D. Specht, U. G€overt, C. Wolff & S.V. Müller

Dementia is an old age disease. Due to dementia disorders the memory will become worse. There is a need for questionnaires to detect dementia disorders in people with an intellectual disability in Germany. We want to improve the early detection of dementia in people with an intellectual disability. We assembled a questionnaire. The questionnaire consists of two parts:

· The first part is called a caregiver interview. Questions about changes of behavior and memory will be asked. We asked these questions to a staff member. The staff member should be familiar with the person with intellectual disability.

· In the second part, the intellectually disabled person should solve simple tasks.

We tested the questionnaire in a study about two-years. Oral Presentation intellectually disabled people participated in this study. These people live in four facilities of intellectually disabled people in Germany. We tested all persons at 6-months intervals. We described progression and onset of dementia disorders of people with an intellectual disability. We found out, that the caregiver interview is better for the early detection of dementia. People with intellectual disability older than 50 years should be interviewed regularly.

## Confirmatory factor analysis and model fit test of assessment index on non-verbal communication for students with profound intellectual and multiple disabilities

K.O. Park & B. Jeon

## Dental attendance among older adults with intellectual disabilities in Ireland

P. McCallion, C. Mac Giolla Phadraig, E. Burke, E. McGlinchey, J. Nunn & M. McCarron

## (Dis-)Empowerment of Participation in Daily Life Communication

S. C. Meier

Aims:

To have influence in daily life interaction is important for people with intellectual disabilities (ID). The way the interaction is going on between support staff and clients influences the opportunity for participation. The aim of the study is to see if and how people with ID can participate in communicative processes in daily life.

Method:

Audio and video data was collected. Participants were six persons (and the persons around them) with mild to profound intellectual disabilities living in Swiss residential homes. Data was analysed with Conversational Analysis. Results of one case will be presented. Results Three remarkable characteristics were detected:

First, daily life in the residence is mainly organized by tasks. Support staff assigns tasks, controls and corrects the performance and validates the result.

Second there is an imbalance of authority and power. Support staff has more and broader possibilities and rights in the interaction.

Third the interaction is highly influenced by scepticism on the side of the support staff.

Conclusion:

Further cases will be analysed to verify these findings and discover new topics.

# The Role of the Support Worker During Peer Interactions Between Children with Profound Intellectual and Multiple Disabilities

S. Nijs, B. Maes & C. Vlaskamp

It is important that children with complex support needs have the opportunities to interact with their peers. We wanted to know how support workers can help children with complex support needs to interact with each other. Our questions were if children with complex support needs interact more with each other when the support worker provides an activity and how the support worker facilitates peer interactions.

Therefore, we videorecorded 14 children with complex support needs when they were together with another child with complex support needs. In that situation no support worker was present. Afterwards we videorecorded the same 14 children when they participated in an activity provided by the support worker together with another child with complex support needs. Then we looked at these recordings and noted which behaviour is shown by the children with complex support needs and the support worker.

The results will be presented during the congress. We saw that children with complex support needs are not more directed towards each other when the support worker is present. The support worker does not succeed in helping persons with complex support needs to interact with their peers.

# Evaluation of a Training Program on Research Methodology for People with Intellectual Disabilities to Enhance their Opportunities to be Co-researchers

J. Fullana, M. Pallisera, C. Puyalto, M. Vilà, M. Castro & E. Català

We have developed a Training Program on Research Methodology for people with intellectual disabilities. Here we present:

- How the program was organized
- What were the contents of the program
- How we evaluated this program
- What results we got from this evaluation

People with ID, teachers and facilitators participated on the evaluation.
We gathered information about: objectives, activities, materials, facilitator role, teacher role, learnings and participants' satisfaction.
We came up with focus groups, interviews and questionnaires to find out information. Results of the evaluation helped us in improving the program.

The evaluation of this program helped us in analysing the usefulness of this kind of programs to help people with ID to participate in research.

## Playworkers' Perceptions of Friendships Among Adolescents with High Functioning Autism/Asperger Syndrome

E. Petropoulou

Aims:

Adolescents who have High Functioning Autism (HFA)/Asperger Syndrome (AS) find it difficult to start a friendship. We need to know why this happens and if play can help them to make friends. There is a playground in Scotland for people with Autism and Asperger which uses play activities, and helps them to socialize.

Method:

We invited eight playworkers who work in this playground and ask them about their opinions and experiences, including why adolescents with HFA/AS have difficulties to make friends, what helps them to start friendships, and finally if play helps and how.

Results:

We found out that adolescents have difficulties to understand what a friend is, to start a conversation, and to express their feelings. The play activities that are used by the playground help them to improve these skills, and make friendships which they keep outside the playground as well.

Conclusions:

Playworkers’ opinions and experiences are important for understanding how play activities help adolescents with HFA/AS to make friends. Findings should be considered by councils, schools, and organizations so as to use play activities as a way to bring together adolescents with HFA/AS, and develop their social skills.

# Sibling Bonds and The Extra-Familial Links Building Process: Subjective and Retrospective Perspective of Adults with Intellectual Disabilities

A.-L. Poujol

In this research, we work through a clinical psychology approach. We collect information about what adults with ID experience in their family and extra-family circles. For example, we need information about:
Sibling bonds
Extra-family links (friends, professional and others).

Childhood, as adulthood, interest us. Thus the creation and the use of social skills will be explored. Furthermore this will be possible both in sibling bonds and in extra-familial links. We will have three meetings with each person:
The first one is an interview. We will speak about family, friends, and other people.
The second one: “The Family Apperception Test": The person will have to create 7 different stories based on 7 different pictures.
During the third one, we will list the person’s relationships (family, friends, professional, and others).

We want to understand what improves or impedes the establishment of links with peers.

## Scoping review of the evidence base for long-term services and supports for persons aging with disability

M. Putnam

## Acceptability of a Multimedia Life Stories Platform in a Residential Home for Individuals with dementia and Intellectual Disability

C. Shivers, M. McCarron, P. McCallion & J. Dinsmore

People with intellectual disabilities and memory problems need help remembering things such as life events and activities they like to do. We think that using iPads, DVDs, and talking picture albums will help these people remember and feel better. We gave three women with intellectual disabilities and memory problems each a photo album with pictures of their life and their family. The photo albums had voice recordings that told the women what was in each picture. We also gave them DVDs with videos from their residence and an iPad to share. The iPad had pictures, songs, and movie clips that each woman enjoyed. We asked the carers to fill out a questionnaire, telling us how often each woman used the items we gave them, and if the women seemed to like each item. We also watched the women to see if they smiled, laughed, or talked more when using the items. The three women seemed to enjoy looking at pictures and listening to music on the iPad and photo albums. We hope to use this information to give more people access to technology to help them remember things that make them happy.

# Aging in persons with Down Syndrome: attention, memory and executive function assessment

S. Signo Miguel, O. Bruna, R. Fernández-Olaria, G. Canals, M. Gimeno, C. Virgili & M. Guerra

# Towards Onset Prevention of Cognition Decline in Adults with Down Syndrome: The TOP-COG Study

C. Stiles , S.-A. Cooper & J. Morrison

Aims:

People with Down’s syndrome sometimes develop memory problems as they get older, such as dementia/Alzheimer’s disease. A medicine called Simvastatin might help slow down memory problems in adults with Down’s syndrome. We invited adults aged 50 or older with Down's syndrome to participate in our study. This part of the study was to find ways we could make this trial better for participants who took part, and to find ways to get more people to join the trial. We wanted to understand why they wanted to participate, how they felt about taking a medication, and what it was like to do the memory tests.

Methods:

We are asking 20 participants and their carers lots of different questions (10 who participated in the trial, 10 who said no). We will look at their answers to the questions using the framework approach, which will let us see what ideas and thoughts they had.

Results:

Interviews are in progress and the results will be available for presentation at the conference.

Conclusions:

We feel that studies like this are important so we can understand how to connect people with intellectual disabilities, their relatives and carers, and service providers to research.

## Expressive vocabulary development in children with Down Syndrome age 18–33 months: profiles and growth patterns

D. te Kaat- van den Os, M. Jongmans, M. Volman & P. Lauteslager

## Safeguarding patients with intellectual disabilities in general hospitals against avoidable deaths and inappropriate commencement of end of life care

I. Tuffrey-Wijne & S. Hollins

## Disseminating research findings to non-academic audiences: 'How to break bad news to people with intellectual disabilities'

I. Tuffrey-Wijne

# Participation of People with Intellectually Disabilities Suffering from Dementia in Residential Facilities

C. Wolff, U. Gövert, B. Kuske, D. Specht & S.V. Müller

Many intellectually disabled people becoming forgetful in old age. Therefore they can do less by themselves. Thereby can to do them less alone. Therefore, they do less in their leisure time.

We wanted to know:
— Which kinds of activities for those people were offered?
— On which way they can easily participate?

We surveyed 12 employees in four institutions. Employees were given different tasks. The answers of the employees we have looked at closely.

We found that:
— because of the forgetfulness people do not join leisure activities
— these people need more help.
— there had to be more specific activities.
— employees had to respond to the wishes of those people

# Work and Employment

## An Investigation into the present conditions and problems associated with sheltered workshops for people with ID

Y. Geshi

## From "Work” to "Work Satisfaction”: Towards a Model of Work Satisfaction in ID Research

A. Kocman & G. Weber

According to the laws in many countries, people with intellectual disabilities (ID) should be able to work just like everybody else.
Currently, we know that people with ID often work in sheltered workplaces.
We also know that many people with ID are very happy when they can work.
However, we don’t really know what aspects of work make them especially happy.
It would also be interesting to know what people with ID don’t like about their work.
There are answers and ideas to these questions from people working in regular workplaces.
We want to know if we can use these answers for people with ID working in sheltered workplaces as well or if there are differences.
This could help including people with ID at work and to supporting them in their work.

## Evaluation of the Inclusion of Teenagers and Young Adults with ID within the Real Opportunities Project in Wales

A. Meek , E. Vigna & S. Beyer

Real Opportunities is a project that works with young people aged 14-19 years old. They all have an intellectual disability or an Autistic Spectrum Disorder. Real Opportunities helps them become independent in their adult lives.

We looked at how the Real Opportunities project helped these young people to do these things: 1) to meet other young people; 2) to do ordinary things in the community and; 3) to make friends locally.

We asked staff working on the project how they helped young people to be more included in their community. We also spoke to 20 families and 20 young people. We asked each person how the project had helped them. We asked:

- What activities people had done?
- How had the project helped the young people and their families?
- Was the project good at helping people be included in their community?
- What stops people being included?

We found that the Real Opportunities project did help young people with intellectual disabilities/Autistic Spectrum Disorder to be included. It helped young people to attend more clubs and other social activities. There were barriers which stopped young people being included in their community. Examples were: Where people live, no clubs or activities in the community, and transport issues. The Real Opportunities project used Inclusion Support workers.

We found that this is a good way to help young people with intellectual disabilities become more included in their local community.

# A good enough job: the path to workplace inclusion in small and medium-sized companies in Italy

E. Zappella & F. Dovigo

# Die Kongressgebäude

Der Kongress findet in Räumen der Universität Wien, des neuen Institutgebäudes (NIG) und der Fakultät für Psychologie statt.

Das ist die Adresse von der Universität Wien:

Universitätsring 1

1010 Wien

Das ist die Adresse vom NIG:

Universitätsstraße 7

1010 Wien

Das ist die Adresse von der Fakultät für Psychologie:

Liebiggasse 5

1010 Wien

# The Congress Locations

The congress takes place in the rooms of the University of Vienna, the NIG and the department of Psychology.

This is the address of the University of Vienna:

Universitätsring 1

1010 Wien

Here you find the NIG:

Universitätsstraße 7

1010 Wien

This is the address of the department of Psychology:

Liebiggasse 5

1010 Wien

# Leitfaden durch das Kongressprogramm

Wir wollen Ihnen ein möglichst spannendes Kongressprogramm bieten.

Es werden sehr viele Vorträge und Diskussionen gleichzeitig stattfinden.

Damit Sie sich leichter zu Recht finden, haben wir einen Leitfaden erstellt.

Im Leitfaden finden Sie die speziell inklusiven Vorträge, Workshops und Diskussionen. Dort wird in leichter Sprache gesprochen.

Natürlich sind Sie aber auch bei allen anderen Programmpunkten herzlich willkommen! Das gesamte Programm finden Sie im Programmheft.

Viel Spaß am 4. IASSIDD Europa Kongress!

# Guide for the congress program

We have given our best to organize an interesting program for you. There will be many talks and discussions at the same time. We have written a guide, which should make it easier for you to come along.

In the guide you find the especially inclusive talks, workshops and discussions. They will be in easy language.

Of course you are very welcome at every other event as well! You can find the complete schedule in the program.

We hope you will have a great time at the 4th IASSIDD Europe congress!

# Leitfaden für Montag, 14.07.2014

Von 09.00 Uhr bis 16.30 Uhr im Prominentenzimmer:
**Workshop für Selbstvertreter zum Thema *„Eine Einführung zu den Kongressthemen“***

Alternativ könnten auch folgende Programmpunkte besonders interessant für Sie sein:

Von 09.00 Uhr bis 10.00 Uhr im Hörsaal 27:
**Workshop für Selbstvertreter zum Thema *„Selbstbestimmt lieben“***

Von 13.30 Uhr bis 14.30 Uhr:
**Führung durch das Museum „Narrenturm“**

Von 17.00 Uhr bis 19.00 Uhr im Audimax:
**Offizielle Willkommensfeier mit Reden von Entscheidungsträgern**

Von 19.00 Uhr bis 20.00 Uhr im Arkadenhof:
**Willkommensgetränk**

# Guide for Monday, 14th of July 2014

09 am to 4.30 pm at Prominentenzimmer:

**Workshop for self-advocates in german language on: *„An introduction to the congress topics“***

As an alternative we also recommend these workshops:

09 am to 10 am at room 27:

**Workshop for self-advocates in German language on: *„Self-determined Loving“***

1.30 pm to 2.30 pm:

**Guided Tour in the museum „Narrenturm“**

5 pm to 7pm at Audimax:

**Official Welcome Ceremony with speeches by decision-makers**

7 am to 8 am at Arkadenhof:

**Welcome Drink**

## Leitfaden für Dienstag, 15.07.2014

Von 09.00 Uhr bis 09.45 Uhr im Audimax
**Keynotevortrag von Marianne Schulze zum Thema *„Unterstützte Entscheidungsfindung“***

Von 10.00 Uhr bis 11.30 Uhr im kleinen Festsaal:
**Keynote Nachbesprechung in leichter Sprache**

Von 12.00 Uhr bis 13.30 Uhr im kleinen Festsaal:
**Vorträge in leichter Sprache zum Thema *„Unterstützte Entscheidungsfindung“***

Alternativ könnten auch folgende Programmpunkte besonders interessant für Sie sein:

Von 10.00 Uhr bis 11.30 Uhr im Hörsaal 30:
**Vorträge in leichter Sprache zum Thema *„Unterstützte Entscheidungsfindung“***

Von 12.00 Uhr bis 13.30 Uhr im Hörsaal 30:
**Vorträge in leichter Sprache zu den Themen *„Unterstützte Entscheidungsfindung“ und „In der Gemeinschaft integriert leben“***

*Mittagspause*

Von 15.00 Uhr bis 15.45 Uhr im Audimax:
**Keynotevortrag von Timothy Shriver zum Thema *„Inklusion im Sport“***

Von 16.00 Uhr bis 17.30 Uhr im kleinen Festsaal:
**Keynote Nachbesprechung in leichter Sprache**

Alternativ könnte auch folgender Programmpunkt besonders interessant für Sie sein:

Von 16.00 Uhr bis 17.30 Uhr im Hörsaal 30:
**Round Table zum Thema *„Unterstützte Entscheidungsfindung“***

Von 17.45 Uhr bis 19.15 Uhr im kleinen Festsaal:
**Round Table zum Thema *„Inklusive Bildung“***

## Guide for Tuesday, 15th of July 2014

9 am to 9.45 am at Audimax
**Keynotespeech by Marianne Schulze on *„Supported Decision Making"***

10 am to 11.30 am at Kleiner Festsaal:
**Keynote-debriefing in Easy Language**

12 am to 1.30 pm at Kleiner Festsaal:
**Presentations in Easy Language on *„Supported Decision Making"***

As an alternative we also recommend these talks:

10 am to 11.30 am at room 30:
**Presentations in Easy Language on *„Supported Decision Making"***

12 am to 1.30 pm at room 30:
**Presentations in Easy Language on *„Supported Decision Making" and „Community based living"***

*Lunch Break*

3 pm to 3.45 pm at Audimax:
**Keynotespeech by Timothy Shriver on *„Inclusive Sports"***

4 pm to 5.30 pm at Kleiner Festsaal:
**Keynote-debriefing in Easy Language**

As an alternative we also recommend this Round Table::

4 pm Uhr to 5.30 pm at room 30:
**Round Table on *„Supported Decision Making"***

5.45 pm to 7.15 pm at Kleiner Festsaal:
**Round Table on *„Inclusive Education"***

# Leitfaden für Mittwoch, 16.07.2014

Von 09.00 Uhr bis 09.45 Uhr im Audimax:
**Keynotevortrag von Lisa Pfahl zum Thema *„Inklusion am Arbeitsplatz“***

Von 10.00 Uhr bis 11.30 Uhr im kleinen Festsaal:
**Keynote Nachbesprechung in leichter Sprache**

Von 12.00 Uhr bis 13.30 Uhr im kleinen Festsaal:
**Vorträge in leichter Sprache zum Thema *„Inklusion am Arbeitsplatz“***

Alternativ könnten auch folgende Programmpunkte besonders interessant für Sie sein:

Von 10.00 Uhr bis 11.30 Uhr im Hörsaal 30:
**Vorträge in leichter Sprache zu den Themen *„Inklusion am Arbeitsplatz“* und *„In der Gemeinschaft integriert leben“***

Von 12.00 Uhr bis 13.30 Uhr im Hörsaal 30:
**Vorträge in leichter Sprache zum Thema *„In der Gemeinschaft integriert leben“***

*Mittagspause*

Von 15.00 Uhr bis 15.45 Uhr im Audimax
**Keynotevortrag von Mary McCarron zum Thema *„Altern und intellektuelle Beeinträchtigung“***

Von 16.00 Uhr bis 17.30 Uhr im kleinen Festsaal:
**Round Table zum Thema *„Inklusion am Arbeitsplatz“***

Von 18.00 Uhr bis 19.00 Uhr im Audimax:
**Offizielle 50. Geburtstagsfeier von IASSIDD.** Es werden führende Personen Reden halten und es wird Auftritte von Künstlern geben.

Von 19.00 Uhr bis 24.00 Uhr in der Technischen Universität Wien:
**Geburtstagsessen und Party**

## Guide for Wednesday, 16th of July 2014

9 am to 9.45 am at Audimax
**Keynotespeech by Lisa Pfahl on *„Inclusion at the workplace“***

10 am to 11.30 am at Kleiner Festsaal:
**Keynote-debriefing in Easy Language**

12 am to 1.30 pm at Kleiner Festsaal:
**Presentations in Easy Language on *„Inclusion at the workplace “***

As an alternative we also recommend these talks:

10 am to 11.30 am at room 30:
**Presentations in Easy Language on *„Inclusion at the workplace“ and „Community based living“***

12 am to 1.30 pm at room 30:
**Presentations in Easy Language on *„Community based living“***

*Lunch Break*

3 pm to 3.45 pm at Audimax:
**Keynotespeech by Mary McCarron on *„Aging and ID“***

4 pm to 5.30 pm at Kleiner Festsaal:
**Round Table on *„ Inclusion at the workplace “***

6 pm to 7 pm at Audimax:
**50. Anniversary Event for IASSIDD.** There will be speeches by leading persons and performances by artists.

7 pm to 12 pm at Vienna University of Technology:
**Anniversary Dinner and Party**

## Leitfaden für Donnerstag, 17.07.2014

Von 09.00 Uhr bis 09.45 Uhr im Audimax:
**Keynotevortrag von Jan Siska zum Thema *„In der Gemeinschaft integriert leben“***

Von 10.00 Uhr bis 11.30 Uhr im kleinen Festsaal:
**Keynote Nachbesprechung in leichter Sprache**

Von 12.00 Uhr bis 13.30 Uhr im kleinen Festsaal:
**Vorträge in leichter Sprache zum Thema *„In der Gemeinschaft integriert leben“***

Alternativ könnten auch folgende Programmpunkte besonders interessant für Sie sein:

Von 10.00 Uhr bis 11.30 Uhr im Hörsaal 30:
**Vorträge in leichter Sprache zum Thema *„In der Gemeinschaft integriert leben“***

Von 12.00 Uhr bis 13.30 Uhr im Hörsaal 30:
**Vorträge in leichter Sprache zum Thema *„In der Gemeinschaft integriert leben“***

*Mittagspause*

Von 14.30 Uhr bis 16.00 Uhr im kleinen Festsaal:
**Vorträge in leichter Sprache zum Thema *„In der Gemeinschaft integriert leben“***

Von 16.15 Uhr bis 17.45 Uhr im kleinen Festsaal:
**Round Table zum Thema *„In der Gemeinschaft integriert leben“***

Von 19.00 Uhr bis 20.30 Uhr im Audimax:
**Abschlusszeremonie**

# Guide for Thursday, 17th of July 2014

9 am to 9.45 am at Audimax

**Keynotespeech by Jan Siska on *„Community based living“***

10 am to 11.30 am at Kleiner Festsaal:

**Keynote-debriefing in Easy Language**

12 am to 1.30 pm at Kleiner Festsaal:

**Presentations in Easy Language on *„Community based living“***

As an alternative we also recommend these presentations:

10 am to 11.30 am at room 30:

**Presentations in Easy Language on *„Community based living“***

12 am to 1.30 pm at room 30:

**Presentations in Easy Language on *„Community based living“***

*Lunch Break*

2.30 pm to 4 pm at Kleiner Festsaal:

**Presentations in Easy Language on *„Community based living“***

4 pm to 5.30 pm at Kleiner Festsaal:

**Round Table on *„Community based living“***

7 pm to 8.30 pm at Audimax:

**Closing Ceremony**

# Leitfaden für Freitag, 18.07.2014

Von 14.00 Uhr bis 15.00 Uhr:
**Führung durch das Museum „Narrenturm“**

# Guide for Friday, 18th of July 2014

2 pm to 3 pm:
**Guided Tour in the museum „Narrenturm“**