



Specialised Social Services: need, policy, case studies

Prader-Willi-Syndrom

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Diakonische Stiftung Wittekindshof, Germany



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Prader-Willi-Syndrom

- Introduction of the syndrome -

Main symptoms of the Prader-Willi-Syndrome

- **Genetic disorder**
- **Rare disease 1 : 20.000**
- **Eating addiction**
- **Mental handicap (80% mild or moderate)**
- **Cognitive deficits (low cognitive flexibility)**
- **Problems in changing the perspective (emotional perspective)**
- **Mood instability**
- **Low competence of self regulation/ self-control**
- **Challenging behaviour (main problem in families or not specialized support)**
- **Metabolic disturbances**
- **Growth hormone and sexual hormone deficits**
- **Skin picking**
- **Diabetes**
- **Sleep apnea**
- **...**

Multiple handicapped people

The past

- Without specialized social services -



Ian on arrival

The future

- with specialiced social services -

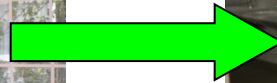
1998



2004



2010



2012



GENERAL INFORMATION ON THE SERVICE

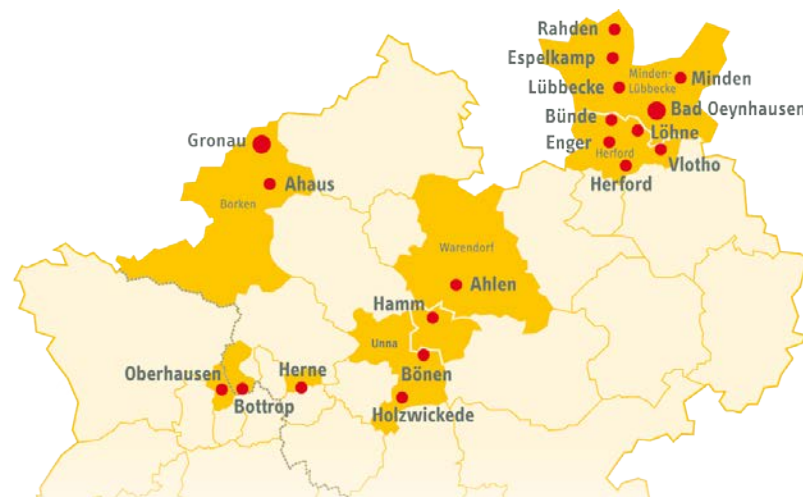
Name of Service: Diakonische Stiftung Wittekindshof

Country: Germany



Foundation 1887 in Bad Oeynhausen

**Today 65 places in
North Rhein Westfalia**



GENERAL INFORMATION ON THE SERVICE

Name of Service: Diakonische Stiftung Wittekindshof

Country: Germany

Type of Service:

- the whole institution “Wittekindshof”: Adapted Housing (AD) / Respite Care Centre (RCS) / Therapeutic Recreation Program (TSR) / Recourse Centre (RC)
- Prader-Willi-Syndrom (mainly): Adapted Housing, but also RCS/TSR/RC

Type of institution: Private foundation

Origins of funding: public funds (98%), individual donors (2%)

Cost for beneficiaries:

- Adults: 0€ if they are not wealthy; Parents from adults pay 59€ per month (group homes) – if you rent your own appartement it depends on your financial situation
- Children pay nothing but Parents from children: it depends on the financial situation of the parents.

Costs for the service (living) between 1000 and 5000€ per month.

GENERAL INFORMATION ON THE SERVICE

Dates/Times of the Year: **all year long**

Target Population: **3500 patients at different locations with different kind of handicaps most with mental handicaps**

– **68 of them with Prader-Willi-Syndrom**

Age-Groups:

- **in the whole institution:
1 to 103 years**
- **in PWS: from 12 to 48 years**



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Target Population: **3500 patients at different locations with different kind of handicaps most with mental handicaps – 68 of them with Prader-Willi-Syndrom**

Age-Groups:

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- in PWS: from 12 to 48 years

Countries of Origin: **Germany, with the focus of the state of North Rhein Westfalia**

Webpage: www.wittekindshof.de/pws

Gronau - Brookstraße



MAIN FIGURES



Total Budget/Year:

Institution: 150 million €

PWS: 4,5 million €

Total Nr. of Beneficiaries/Year:

Institution: 3500

PWS: 68

Total Nr. of Permanent Staff:

Institution: 3000

PWS: 80

Total Nr. of Intermittent Staff:

Institution: 100

PWS: 0

Nr. of Volunteers/year:

Institution: 100

PWS: 0



BRIEF HISTORY (PWS)

Date of Start: August 1998

Created by:

Foundation Wittekindshof with the projektmanager: Dr. Norbert Hödebeck-Stuntebeck),
The PWS Parent Association Germany were involved in initiating this process

Short History:

- Start 1998 - group home – 6 adult people with PWS – rurale, country side placement – with working places in a sheltered workshop (Schloss Benkhausen)
- 2000 second group home – 8 places (6 small group + 2 apartment places) – places in the village (Lübbecke)
- 2003 starting seminars for parents and for people with PWS
- 2007 starting support for people with PWS and their families in the family
- 2008 starting the curricula for the staff in PWS



BRIEF HISTORY (PWS)

- 2008 group home - 12 places (small groups of 2 + 4 + 6 places) in the centre of a city (Herne)
- 2010 group home for children and youth – 7 places in a city (Gronau)
- 2013 12 places (6 x 2 apartments) in the centre of a city (Oberhausen)
- At each city (Lübbecke/Herne/Gronau/Oberhausen) where we have PWS offers we organised it as a form of a Ressource Centres (RC)
- Organisation of national and international conference every year since 2008.

Gronau - Brookstraße



BRIEF HISTORY (PWS)

Characteristics of quality today:

- **Differentiation in the group homes in small groups at each facility and for special need for people with PWS like: high function, slow tempo, young adults,**
- **School or work offer at each facility.**
- **Consulting for people with PWS in their families and for the families at each facility (Resource Centre)**

BRIEF HISTORY (PWS)

Were patients involved in the creation process?

Indirect by the PWS parent association

In 1996 we had a patient with PWS (what was totally unknown for us)
and there were also an initiative from the PWS parent association Germany to our institution “Can you help”

There were a first information about the syndrome by parents (parent association) The result was “We have to do”

The patients were in the way involed as they live with us and we learn with them.

Many things we do today – we do because we learnd in the interaction with them. “Ask them!!!” was the most important note I gave to the staff.



GOVERNANCE AND MANAGEMENT of the institution (Diakonische Stiftung Wittekindshof)

Currently managed by: **Foundation**

Funded by: **public funds, individual donors (small part)**



Governance structure: (nr of people and general profiles of board members and members of advisory committee if there is one)

Two Directors (Theology, Economic)

7 Ressort Leaders (second level) (Theology, Economic, Paedagogic, Law)

Unit managers (third level) (paedagogic, nursing)

Are patients/patient representatives involved in the governance process? **Patients are involved by “Patients advisory board”, (for work, for living) people with PWS were temporarily members of this board.**

Parents advisory board

How many? **The “patients advisory board” (work/ living) have each 12 members and they will be elected by all patients of the whole institution.**

The “Parents advisory board” has 10 members, elected from all parents.

What is their role and their scope of action?

All advisory boards have periodically meetings with the first and second level of the management. They get information about the economic numbers and about the new plans of developments in the institution and discuss this with the government of the institution. They develop ideas gave reflections to themes: living, working, nutrition, roles, ...



QUALITY ASSESSEMENT

Are patients evaluating the service after attending? **No**

Is the service accredited by any authority performing quality control?

Yes, by different authorities of the public government (in processes and in structures)

Is the service connected to a Centre of Expertise/Hospital?

The whole institution: Yes, by different Centres

Special to PWS

- University of Essen - Faculty of Human genetics: getting diagnosis and work together to develop new research themes in PWS
- University of Essen - Faculty of Endocrinology: communication and information about hormones and hormone-treatment
- St. Bernward Hospital in Hildesheim: working on individual nutrition-treatment by children and adult with PWS
- Heart and Diabetes Centre of North Rhein Westfalia, Bad Oeynhausen: interacting by questions of diabetes, make research together
- ...

QUALITY ASSESSEMENT

-The cooperation with all this extern experts helps to increase the quality of care in a high level.

We are working as a “Centre of Expertice” for other PWS group homes, for people with PWS, for parents, for teachers , ... in themes of psychology and paedagogic.

People with PWS are involved in this development of concepts for other PWS offers



10 Guiding Principles for Specialised Social Services

1) Rights and Personal Identity

The existing offers are open for all people with diagnosed PWS (children and adult) from North Rhein Westfalia.

There are individualized support concepts for everyone with PWS.

We support other institutions in regions where no special offers for PWS are.

We build up new PWS offers in regions where no institutions are.

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2) Person/Family Centeredness

In the PWS group homes:

Individualized support concept which includes: nutrition, physical activities, behavioral treatment, work/school, ...

Lifespan orientated offers: for children, youth and adults, school, work training, work ...

what we have to develop is a training for the early childhood and the childhood period.

Periodically “parent/ family days” in the group homes

Individualized face to face meetings between parents and professional caregivers

In or for the families:

individualized consulting with the child, youth or adult and the family

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3) Holistic, Comprehensive, Integrated Approach

The staff is a multidisciplinary team: paedagogics, nurse, social worker, psychologists...

Regular cooperation with:

- the school or the sheltered workshop
- Families
- Physicians
- Parent association

Getting and asking for information from external national and international experts

All the offers are “inclusive” offers (placed in the society), placed in the cities.

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4) Governance Structure

(slide “Governance and Management”)

Qualification/ education of the patient advisory board

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5) Organisation and Administration

- The institution have a Mission statement of the Institution
- There is a Strategic masterplan 2013/ 2018/ 2026 for the whole institution
- We have a quality-management-system with internal auditing processes
- All patients have a regular service contract for living and or working
- We use a documentation system - computer based
- We have Multidisciplinary Quality-Circles for: PWS, Autism, Challenging behavior, older people with handicaps, ...

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6) Evaluation and Permanent Improvement of Quality

We are part of a Benchmarking process in Germany between social services

We have a quality-management-system with internal auditing processes for all processes and structures

We have a Curricula for the staff in PWS

We organize National and international conferences for PWS

We do research: “Change of perspective by PWS” Hödebeck-Stuntebeck, 2012

We start Developments of training programs: “Social competencies in PWS” Hödebeck-Stuntebeck, 2012

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7) Connection to Centres of Expertise/Medical Institutions

We are in cooperation about PWS with:

- University of Essen - Faculty of Human genetics: getting diagnosis and work together to develop new research themes in PWS
- University of Essen - Faculty of Endocrinology: communication and information about hormones and hormone-treatment
- St. Bernward Hospital in Hildesheim: working on individual nutrition-treatment by children and adult with PWS
- Heart and Diabetes Centre of North Rhein Westfalia, Bad Oeynhausen: interacting by questions of diabetes, make research together

Working together with:

- PWS association of Germany
- International PWS Organisation (IPWSO)
 - N. Hödebeck-Stuntebeck - Chairman of Professional Provider Caregiver Board of IPWSO

Editing of the “Best practice guidelines for PWS”

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8) Admission Procedures and Individual Assessment

Concept of the different parts of the PWS support

We have a regular and defined admission process

There is every time a personal contact before an admission

We have the chance to offer a short term support if helpful

Every time the patients of the group home are involved in this process

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9) Training of Staff and Volunteers

We have a special PWS Curricula with 10 modules (130 hours)

3 Basic modules

- Introduction into the PW syndrome (1/2 day)
- Behavior analyses (1 day)
- Behavior modification (1 day)

7 Specialised modules

- communication (1 day)
- nutritionmanagement (1 day)
- neuropsychology (1 day)
- case supervision (1/2 day)
- internship in work or school (2 days)
- team supervision (3 days per year)
- De-escalation training (3 days)

New staff members have to use the basic modules in the first 3 month after starting the work in a PWS offer.

All 10 modules have to use in the first two years after starting work in a PWS offer.

The seminar leaders are internal and external PWS experts

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10) Rare Diseases and Health Care Needs

The special health care needs are in the focus by the special members of the supporting team:

Paedagogics

Nurses

Specialist for nutrition in cooperation with a nutritionist

Psychologist (in every team)

In case of the massive behaviour problems we are in contact with the local psychiatries

We have regular contact with the physicians of the patients if they allowed it.



Thank you!

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